



Family Rights Handbook



Kentucky Public Health
Prevent. Promote. Protect.

*The cost of printing was paid from state funds through the Department for Public Health,
First Steps Program, pursuant to KRS 57.375*

Introduction

This handbook describes your rights as defined in Part C of the Individuals with Disabilities Education Improvement Act (IDEA). IDEA is a federal law that includes provisions for early intervention services for eligible infants and toddlers, birth through two year of age, with developmental delays and their families.

The Department for Public Health within the Cabinet for Health and Family Services is the lead agency that administers the Kentucky Early Intervention System which is known as First Steps. First Steps contracts with fifteen Points of Entry (POE) across the state to provide services to infants, toddlers and their families. The First Steps program is designed to:

- enhance the development of infants and toddlers with disabilities and minimize their potential for developmental delay;
- recognize the significant brain development that occurs during a child's first 3 years of life; and
- enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities.

Families involved with the First Steps program have legal rights and procedural safeguards to protect parents and children. Families must be informed about these rights and procedural safeguards throughout their enrollment with First Steps.

In order for your family to receive the maximum benefits from early intervention services, it is important for you to fully participate. You are a key decision maker and know the needs of your child and family best. You are your child's best advocate throughout his/her life.

The Service Coordinator and service providers working with your family can help you understand your rights and responsibilities, including the information contained in this handbook. A Parent Consultant is also available to provide assistance and answer any questions you might have about the program. Your Service Coordinator can give you the contact information for the parent consultant upon request.

Summary of Your Family's Rights

Your Family Has The Right To:

- Receive screening, evaluation, assessment, IFSP development, service coordination and procedural safeguards at no cost.
- An evaluation, assessment, and if the child is eligible, a meeting to develop an Individualized Family Service Plan (IFSP) within 45 days of referral to First Steps.
- Understand and receive information in your native language or other way of communication that you use. This includes information given to you verbally and written.
- Appropriate early intervention service for your child and family as described in the IFSP.
- Receive early intervention services in settings where infants and toddlers without developmental delays and disabilities are typically found. These settings are referred to as the natural environment.
- Give your written consent before the screening, initial evaluation, and assessment are conducted and when beginning early intervention services. Your consent is voluntary and may be revoked at any time.
- To refuse a service without risking other services.
- Be invited to and participate in all IFSP meetings.
- Confidentiality of personally identifiable information.
- Review and correct early intervention records.
- Receive written notice five (5) calendar days before a change is proposed (or refused) in the identification, evaluation or in the provision of services to your child and family.
- File a complaint if you believe your rights have been violated.
- Request mediation and/or due process hearing to resolve disagreements you may have with the early intervention program.
- Bring an advocate, friend or attorney to all meetings with First Steps.

Procedural Safeguards

Throughout your involvement with First Steps you are assured certain protections, known as Procedural Safeguards, and are entitled to be notified of them. These are described below.

Prior Notice

Prior written notice must be given to you a reasonable time (within five (5) days) before the First Steps program proposes or refuses to initiate or change the identification, evaluation or placement of your child (including transition at age 3) or the provision of appropriate First Steps services for your child and family.

- The notice must inform you about:
 - The action that is being proposed or refused;
 - The reason for taking the action; and
 - Your rights and procedural safeguards available under First Steps, including filing a complaint or request for mediation.
- The written notice must be:
 - Provided in your native language unless it is not possible to do so;
 - Explained to you in your native language or other mode of communication;
 - Understood by you.

Consent

Consent means that you have been fully informed of all information related to the activity for which your consent is needed and understand and agree in writing to that activity.

- Your consent is needed before First Steps can:
 - Complete a developmental screening of your child;
 - Evaluate and assess your child;
 - Conduct a family assessment;
 - Share information about you or your child;
 - Provide early intervention services.

Your consent is voluntary and you can revoke your consent at any time. You may choose to not give consent for any particular service without risking other services, and may refuse a service at any time, even after accepting it, without affecting other intervention services.

The consent form you sign must describe the proposed activity and, if related to the release of information, list the records that will be released and to whom.

If consent is not given, First Steps shall make reasonable efforts to ensure that you are fully aware of the nature of the screening, evaluation, assessment, or the services that would be available. First Steps shall make reasonable efforts to ensure that you understand that your child will not be able to receive the screening, evaluation, assessment, or services unless written consent is given.

If your failure to give consent constitutes neglect under Kentucky law, a report will be made to the proper authorities as required by state law.

Records

Right to Inspect and Copy:

- You have the right to inspect and receive a copy of the information that First Steps has about you or your child in most situations. This includes medical and billing records.
- You must submit your request in writing to your local Point of Entry (POE), and include a time period for which you wish to receive your records.
- You may be charged a reasonable fee, unless such a fee would prevent you from exercising this right.
- The POE must respond to your request within ten (10) days.

Right to Request Amendment:

- You have the right to ask First Steps to amend the health information it has collected or maintains information about you or your child that you feel it is incorrect or incomplete.
- If your request is approved, your request and the amendment will become part of your permanent record.
- You must submit your request in writing to the First Steps State Lead Agency at the following address: 275 E. Main St., HS2W-C, Frankfort, KY, 40621.
- You must state the reason you are requesting an amendment.
- If the State Lead Agency refuses to amend the record you will be notified of this decision in writing.
- If you disagree with the decision of the State Lead Agency you have the right to request a due process hearing.

Right to a List of Types and Locations:

- You have the right to request a list of the types and locations of information about you or your child collected, used or maintained by First Steps.
- This request must be submitted in writing to First Steps State Lead Agency at the following address: 275 E. Main St., HS2W-C, Frankfort, KY, 40621.

The early intervention record that is established for your child is confidential. However, the law allows the following people to have access to the confidential file for administration and implementation of First Steps:

- the POE Manager in charge of the Point of Entry (POE);
- all individuals providing early intervention services to your child;
- POE staff who must access your child's file to perform assigned duties such as the administrative assistants, District Child Evaluation Specialist, the service coordinator assigned to your child, and,
- First Steps State Lead Agency staff as required for supervision and monitoring.

Personally identifiable information is shared (disclosed) to health insurance companies with your consent and Medicaid for payment of services. A non-custodial parent may have access to a child's educational record except when a court order preventing this access is on file.

Certain records may be released from your child's file without your permission to individuals who have an educational need to know. Such individuals include other POEs to which child is transferring, federal data report collection contractors, and school district of residence representatives when the child nears his third birthday and will transition out of First Steps. Records will also be released to comply with a judicial order or lawfully issued subpoena, to state and federal officials for the purpose of an audit, and to accrediting organizations to perform accrediting function. Personally identifiable information from the educational record may be disclosed in an emergency, such as a medical emergency or to child protective services, if the information is necessary to protect the health and safety of the child.

Privacy

The First Steps program collects and maintains information about your family, including information regarding program eligibility, diagnostic information and financial information. This information is maintained in both an electronic developmental record and hard copy record. Information about your child is confidential and cannot be shared with others without your written consent.

First Steps ensures your privacy in the following ways:

- All Point of Entry (POE) and early intervention provider activities shall be conducted in ways that are consistent with confidentiality and other record provisions as set forth in the Health Insurance Portability and Accountability Act (HIPAA), (Public Law 104-191, Title II, § 262(a), 100stat. 2024), the Family Educational Rights to Privacy Act (FERPA) (20 USC 1232g), and other pertaining laws.
- All early intervention providers, including POE staff, shall protect the confidentiality of personally identifiable information at collection, storage, disclosure and destruction stages.
- POEs and early intervention providers will maintain a hard copy case record for your child. This record will contain copies of any documents that you had to sign and copies of any letters or notices you received.
- Your child will also have an electronic record in the First Steps online data management system known as TOTS. Your child's TOTS record will contain the evaluation and assessment reports, a copy of the IFSP, the provider's service notes and progress reports.
- All case records are the property of the First Steps Program. This record shall be separate from clinical records if the provider also provides treatment or therapy. Hard copy case records are maintained by the early intervention providers, including POEs, in a secure location. A working file may be copied for use in satellite offices and in the field.
- Records will be maintained for a period of at least six years from your child's discharge from First Steps services or longer if administrative or legal action is pending. Destruction of records shall be consistent with pertinent laws.
- The POE office or early intervention provider shall notify you in writing upon discovery of a breach of confidentiality or any time you or your child's personally identifiable information may have been compromised.

When You Think Your Rights Have Been Violated

Resolving Disagreements

If you disagree or are dissatisfied with the services your child is receiving you should first speak with your Service Coordinator about the situation and try to resolve it with your IFSP Team. If you are not able to come to an agreement or your dissatisfaction is with your Service Coordinator, you should ask to speak to the POE Manager so that you can discuss your concerns with them. You can also contact the Parent Consultant if you are still not able to come to a resolution and you don't want to file a formal complaint. Contact information for the Parent Consultant is available from your Service Coordinator or State Lead Agency staff. It is also available on the First Steps website: <http://chfs.ky.gov/dph/firstSteps/helpfulstaff.htm>

Filing a Complaint

You may file a written complaint. The written complaint must be signed by you and include:

- your name, address, and phone number;
- the name and address of the program or person that you are complaining about ;and,
- a statement of what the complaint is about, including the facts that are the basis for the complaint

You should also include a statement of how you would like the complaint to be resolved.

When filing a formal complaint, you must also forward a copy of the complaint to the program or provider who the complaint is about.

You may be contacted to see if you have any additional information you want to submit before a final decision is made. It is helpful to include the best times to contact you by telephone in the complaint.

You will receive a written decision within sixty (60) days that addresses each allegation in the complaint and includes the facts and conclusions, the reason for the decision and the corrective actions, if needed that will be taken.

Your Service Coordinator can provide you with a copy of the First Steps Complaint Form. This form should be sent to:

First Steps
275 E. Main St., HS2W-C
Frankfort, KY 40621

Mediation

You may request mediation to resolve disagreements regarding the identification, evaluation and assessment, eligibility determination, placement or the provision of appropriate early intervention services for your child and family. The mediation process, including a written agreement, shall be completed within thirty (30) working days of the receipt of the request for mediation.

- Mediation is voluntary and can be chosen first if there is a disagreement between you and your early intervention providers.
- Mediation does not have to be chosen before a formal due process hearing and does not delay your right to request a hearing.
- During the mediation process, services must continue, unless you as parent/guardian choose not to continue services for your child. If the complaint involves the request for initial services, your child must receive the services not in question.
- You or the party involved may waive mediation. If the party involved waives mediation, as parent/guardian you must be notified within two (2) working days of this decision.
- At any time during the mediation process, you may request a due process hearing.
- Either party may request that the mediator grant an extension of the thirty (30) day timeline. This extension will be granted if there is a good cause (exceptional circumstances). An extension may not be longer than thirty (30) calendar days unless the party who asked for the mediation agrees to a longer period of time.

- Mediation resolutions may not conflict with state or federal laws and must be to the satisfaction of both parties. Both parties must sign the written resolution to prove their satisfaction with the resolution.
- The mediator shall mail a copy of the written resolution to each party within five (5) calendar days following the mediation conference. The mediator shall also file a copy with the Cabinet for Health and Family Services.
- All discussions that occur during the mediation process are confidential. These discussions may not be used as evidence in any subsequent due process hearings or other court proceedings. You may be asked to sign a confidentiality pledge prior to the start of the mediation process.

Due Process

A due process hearing is the most formal way to resolve disagreements between you and the First Steps system. You may request a due process hearing to resolve disagreements regarding the identification, evaluation and assessment, eligibility determination, placement or the provision of appropriate early intervention services for your child and family. You may request a due process hearing in addition to requesting mediation or filing a complaint. The due process hearing described in this section must be carried out at a time and place that is reasonably convenient to you.

At the due process hearing you may:

- Be accompanied and advised by lawyer (at your expense) and/or by individuals with special knowledge or training about infants and toddlers with developmental delays.
- Present evidence and confront, cross-examine, and compel the attendance of witnesses.
- Stop the introduction of any evidence at the hearing that has not been made known to you at least five (5) days before the hearing.
- Obtain a written or electronic word-for-word record of the hearing upon written request.
- Receive written findings of fact and decisions at no cost to you no later than thirty (30) days from the receipt of the request for a due process hearing. Extensions beyond the thirty (30) day timeline may be granted by the hearing officer if requested by either party.

During the due process hearing proceedings services to your child must continue, unless you choose not to continue services. If the request for due process hearing involves the request for initial services, your child must receive the early intervention services not in question.

If you are not satisfied with the findings and decision of the impartial due process hearing, you have the right to bring civil action in state or federal court.

To request Mediation or Due Process

Your Service Coordinator can provide you a copy of the Mediation/Due Process Request form. This form should be mailed directly to:

Division of Administrative Hearings
Cabinet for Health and Family Services
275 E. Main St.
Frankfort, KY 40621

Definitions

Advocate: A person you choose who helps you understand and decide what services your child may need and how to use the rights provided by law.

Confidentiality: Keeping information about you and your child private.

Consent: This means that you have been fully informed of all information relevant to the activity for which consent is sought, in your native language or other mode of communication; you understand and agree in writing to the carrying out of the activity for which consent is sought, and the consent describes that activity and lists the records (if any) that will be released and to whom; and you understand that the granting of consent is voluntary on your part and may be revoked at any time.

Destruction: the physical destroying of the early intervention record.

Due process: A formal administrative process in which you, or your representative, may present evidence before an impartial hearing officer regarding the identification, evaluation and assessment, eligibility determination, placement or the provision of early intervention services for your child.

Evaluation: The procedures conducted to determine if your child is eligible for First Steps services. These procedures may include the gathering of existing information about your child as well as conducting assessments (tests) to learn more about your child's development.

Mediation: An informal process requested by you, or your representative, to resolve disagreements regarding the identification, evaluation and assessment, eligibility determination, placement or the provision of early intervention services for your child.

Native language: The language or mode of communication you typically use.

Parent: The natural or adoptive parent or legal guardian authorized to act as the child's parent, who can make educational decisions for a child enrolled in First Steps services. This can include a person acting in place of a natural or adoptive parent, such as a grandparent, step-parent or other relative with whom the child lives, or a person legally responsible for the child's welfare, such as a foster parent.

Permanent record: Your child's official First Steps early intervention record.

Personally identifiable information: Any information that would reveal the identity of you, your child and family.

Point Of Entry (POE): The office that accepts referrals and will assist you with your child's eligibility determination for First Steps. Also known as the Local Lead Agency (LLA).

Procedural safeguards: The provisions in IDEA that protect you and your child's rights with respect to the provision of appropriate early intervention services.

Redaction: Revision of the early intervention record to ensure that personal identifiers are removed.

Service Coordinator (SC): The person who will assist your family through the intake, evaluation and eligibility determination process and facilitate the IFSP development. Your Service Coordinator can also provide information about and make referrals to other community resources and coordinate and ensure the delivery of all services.