



Understanding The First Steps Early Intervention System

A Family Handbook



This handbook is a publication of the First Steps Early Intervention System.
Copies of this document may be made for distribution to families participating in
First Steps. For additional information contact:

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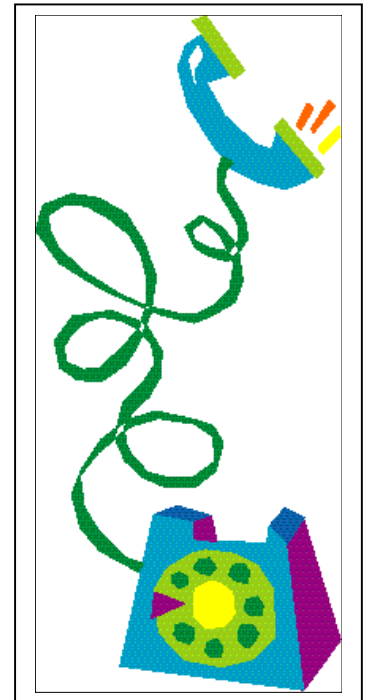
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Welcome to First Steps.

The purpose of this handbook is to provide an explanation of the First Steps Early Intervention System. Your child has been referred to your local First Steps System Point of Entry (SPOE) because of a concern about your child's developmental progress. This handbook will help you understand all of the opportunities First Steps has available to your child and to your family.

The handbook will serve as a guide through the process of eligibility determination, service identification and service implementation. The manual provides basic information as your family moves through the intake process at the System Point of Entry all the way through the development of your child's first Individualized Family Service Plan.

Always feel free to ask questions and ask people to talk to you about your concerns. The First Steps system is designed to support your child and your family. Be an active participant in your child's development.



MEETING THE INTAKE COORDINATOR

During the intake meeting, you will be asked to review and sign a lot of papers. This paperwork ensures that your rights as the parent, are being met. If you need more explanation regarding a form, ask your intake coordinator to go over the information again.

Although every family is different, the forms that you will be asked to sign, are similar. Here is a list that the intake coordinator will go over with you:

- *Consent form to establish an electronic record for your child.*
- *Consent for an evaluation.*
- *Permission for each of the providers that you have chosen to be given information about your child in order to evaluate your child's eligibility.*
- *A form stating that you have been explained your rights.*

Once your child has been referred to First Steps, an intake coordinator from the local SPOE will contact you. The intake coordinator will explain the purpose of First Steps and discuss the concerns that you have regarding your child's development. The job of your intake coordinator is to explain the First Steps program and coordinate the eligibility process. If your child is eligible, the intake coordinator will help you through all of the steps to your first Individualized Family Service Plan (IFSP).

The intake coordinator will start the process by setting up a time to meet with you to explain the First Steps program. This meeting may be called an intake meeting. The meeting will be scheduled at a time and place that is convenient to you and your family. Meetings may take place in your home, at your work, or at a community site.

During this visit, you will be asked to share information about your child and family. The intake coordinator will ask you about past medical care that your child has received, as well as concerns that you may have. You will also be asked to sign forms that give the intake coordinator consent to proceed in the intake process.

During this intake meeting you can expect to:

- Receive information or brochures that describe the First Steps program and your rights.
- Review your rights in the program.
- Discuss the referral and concerns for your child's development.
- Explanation of the evaluation process.
- Presentation of providers that are available in your community to assist in the evaluation process.
- With your permission, help arrange for your child's evaluation.
- Give your permission to continue with the process into First Steps.
- Discuss other needs or concerns that you may have and assist in the application or referral process to programs that may be able to help. This may also include gathering insurance information to help you in understanding your benefits.

IS MY CHILD ELIGIBLE?

If you decide that the First Steps program can help your child, the next step is to see if your child is eligible for the program. This is accomplished by participating in an evaluation.

In planning for your child's evaluation, the intake coordinator will discuss your concerns regarding your child and will help to identify possible tests that may need to be done. While each child's evaluation will be different based on their needs, there are certain components that all families can expect to occur.

Every evaluation will involve:

- Gathering current and past medical information to provide a health assessment.
- Gathering information from past screenings or assessments that have been done.
- Talking about your concerns and what activities you see your child doing.
- Involvement of at least two providers from different areas or disciplines to review information regarding your child's development.
- The decision as to whether or not your child is eligible for the First Steps program.

Depending on your child's needs, you may experience some or all of the following activities:

- Your child may participate in a test or assessment to measure areas of development in which you have a concern.
- You may be asked to play with your child-or a provider may want to play with your child to watch what your child can do.
- If your child has a diagnosis, a medical statement may be requested from your child's doctor.

You have an important role to play in your child's evaluation. Here's a list of suggestions about ways you can participate in your child's evaluation:

- You can sit beside or hold your child.
- You can help with activities that explore your child's abilities.
- You can tell team members about whether what they are seeing is typical of your child.
- You can help the team see your child's strengths and needs.
- You can comfort and support your child.

You can ask questions and offer your opinions about how your child's evaluation is going.

PLANNING FOR THE EVALUATION

- *What type of information would be helpful for people to know about your child?*
- *Have other professionals, such as a doctor, seen your child? Were any concerns noted during the visit?*
- *If your child is going to participate in a test or see a provider to assess their development, where do you want your child to be seen? Where do you think your child will do their best?*
- *What time of day will your child do best?*
- *Is there someone else you would like to participate in your child's evaluation? A relative, friend, or caregiver who knows your child well?*
- *Try to think about your concerns and questions before meeting with the intake coordinator. Make a list to have with you.*
- *Think about your daily routines with your child (eating, sleeping, playing, bathing, etc.) Does anything happen at these times that concerns you? For example, getting your child to eat is difficult due to problems with sucking or swallowing.*

You have a wealth of information regarding your child. Ask questions, provide input, and SHARE your thoughts and concerns.

The First Steps program has rules to make sure your child's evaluation is fair. They are:

- *Your child's evaluation team must use materials and activities that are sensitive to your family's language. The evaluation must be completed in the primary language means the language you most often use when speaking to your child.*
- *The cultural background and traditions of your family must be considered in your child's evaluation. Families raise children using their own cultures and ideals. Your child's evaluation team must take this into account in deciding what materials to use and describing your child's responses to the evaluation.*

A child is eligible for First Steps when he/she has:

- *A medical diagnosis known to cause or contribute to developmental delay;*
- *A documented delay of 25% in one developmental area or 20% delay in two or more developmental areas*

After the intake coordinator has gathered the information from the evaluation process, you will have an opportunity to discuss the information. Make sure that your concerns are addressed. Ask questions! Be honest about what you do or do not understand. Let the intake coordinator know if your opinion is different from the one presented.

The Intake Coordinator will need to complete paperwork that documents the findings of the evaluation. This document will include:

- A summary of concerns regarding your child's development.
- A statement about your child's eligibility for First Steps.
- The names of the professionals who evaluated your child.
- A summary of what information was gathered about your child.
- The tests and scores that were used (if any) and what they mean.

The discussion of your child's evaluation results must be conducted in your primary language to ensure that you understand and make an informed decision about what is being discussed. If necessary, a translator will be provided to allow you to participate in the discussion.

After the multidisciplinary team reviews all of the evaluation documentation, there are three possible results:

- Your child is eligible and in need of services;
- Your child is eligible but not in need of services; or
- Your child is not eligible.

Eligible and In Need of Services:

If your child is found eligible and in need of service, a team of providers selected by you will begin to work with you and your child to develop a service plan. Eligibility is established for one year. On an annual basis a team of providers working with your child and your family will re-evaluate eligibility and need for service.

Eligible But Not In Need Of Services:

There are times when a child is eligible for First Steps, but the evaluation team does not feel that the child is in need of early intervention services. If this is the situation with your child, take a moment to celebrate your child's development -- but, before you exit the system, ensure that you receive information describing the developmental levels you should expect from your child and now to contact the system in the future, should you have concerns.

If you disagree with the team's decision that your child is not in need of early intervention services, ask for reconsideration. You may do this by providing additional information, or requesting that additional tests, or assessments be provided.

Not Eligible For Services:

Some children who are referred to the First Steps program do not meet the eligibility guidelines for the program. Typically this is good news for the family, because the child is developing within a normal range. For some families, however, there will continue to be concerns and they may not agree with the decision of the team. If this happens, the family should review their concerns with the intake coordinator and share why they feel the child is eligible. They should also request that the child's eligibility be reviewed and that if possible, additional information or tests be completed. This gives the team the opportunity to review documentation to ensure that the right decision was made. If the parent continues to disagree with the team, the family may write an appeal to the Bureau of Child Development. Your intake coordinator can help you with the letter and better explain all of your rights.

If you agree your child is not eligible - and still feel you need help - ask your intake coordinator for information about other supports and services in your community. They may be able to connect you with those programs.

FAMILY ASSESSMENT

Every family is different. You know your family best - and what you can do to help your child's development. You know what is most important to you, your child, and family - and what concerns you most.

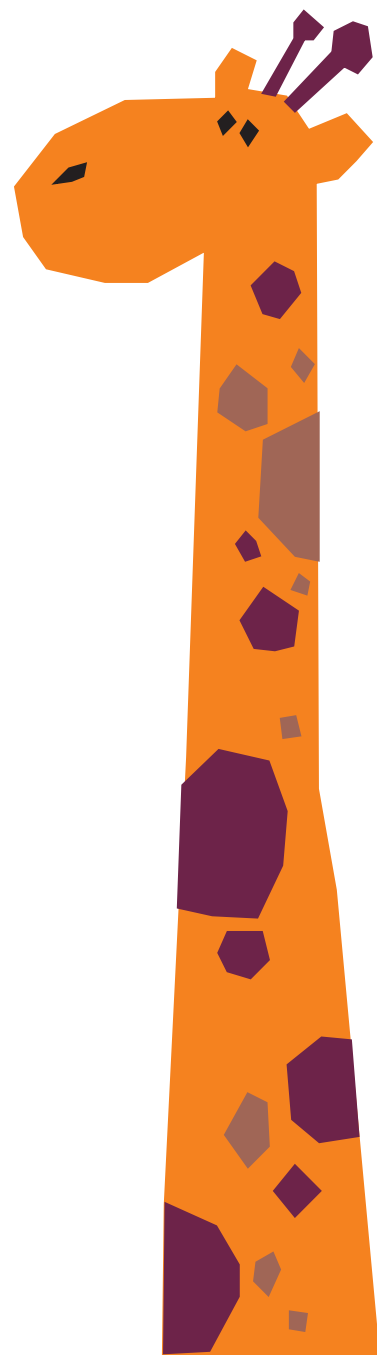
As a parent, you bring your resources, priorities and concerns to the early intervention process. **Family resources** are the strengths, abilities and supports that families can use to help their child. **Family priorities** are the outcomes that you want most from early intervention services.

Family concerns are the issues or needs you want to work on with your child and family.

The identification of your resources, priorities and concerns called "family assessment" can be helpful in designing the plan of care known as the **Individualized Family Service Plan (IFSP)** for your child and your family. If you wish, you can participate in a family assessment. The family assessment is a voluntary process.

All information shared is kept private. If you decide to participate in a family assessment, it can help you:

- Think about what you need most from early intervention services;



Here are suggestions to think about in planning for your IFSP meeting and what you may want to talk about with your intake coordinator:

- *How would you describe your child to others?*
- *What is working well for you at home?*
- *What do you need help with?*
- *What help do you want for your child?*
- *What type of information do you need? (information on diagnosis, child development, etc.)*
- *What activities do you want your child to take part in?*
- *What does your current schedule look like?*

You are a key member of the IFSP Team! This Team works to develop outcomes in the IFSP. These outcomes are based upon your concerns and the individual needs of your child. Services are identified to support these outcomes

- Think about other services and supports you might need (like another parent to talk to or information on a diagnosis);
- Get referrals or information on other programs that your family may want or need; and
- Prepare for your IFSP meeting.

Your family assessment will be:

- Completed with you by the intake coordinator, at a time and place good for you.
- Based on information provided by you and your family in a personal interview.
- Your description of your family's resources, concerns and priorities.

DEVELOPING A PLAN FOR SERVICES AND SUPPORTS

If your child is eligible for the First Steps Program, the next step is to develop an **Individualized Family Service Plan (IFSP)**. Your IFSP must be completed 45 days after your child's referral to First Steps, unless YOU "stop the clock" (for example, if your child is sick and the evaluation must be delayed). The IFSP is the written plan for early intervention services your child and family will receive. You will work on this plan at an **IFSP meeting**. Your intake coordinator will discuss with you what happens at the IFSP meeting and help you prepare. Some facts you need to know are:

- The IFSP meeting must be held at a time and place that is good for you and your family.
- You, your intake coordinator and the persons who participated in the evaluation must be involved in the IFSP planning.
- You may invite others to be at the IFSP meeting - such as family, friends or your child care provider.
- Your intake coordinator may invite others to the meeting with your permission.
- You can ask an advocate to take part in the meeting.
- You need to give permission to use any information from your family assessment, if you had one.
- You will be asked to select an **ongoing service coordinator** who will work with you and your family to implement the IFSP.
- The meeting will be held in the language you speak, unless it is clearly impossible to do so.

Before the meeting, your intake coordinator will make sure you understand your child's evaluation. She or he will also talk with you about the possibilities for early intervention services.

The IFSP contains the services that are identified by the team that will address your child's developmental needs and assist your family to meet the special needs of your child. There may be other services that your child and/or family needs that are beyond the scope of the First Steps system. Your IFSP Team will help to identify community resources to assist you to meet these needs.

Early intervention services are individually identified and planned to meet the specific needs of your child and family. No two IFSPs should look alike. Service needs should change over time and the IFSP should be revised to include these changes.

Where are services provided?

You will be asked early on to identify the daily routines, activities and settings that your child participates in. You should begin by asking yourself "where is my child right now?" One good example of a natural setting for a young infant is a child care center if (both) parents work. Another common setting is your home and neighborhood. Natural settings are not just locations, but include people too. They could be your child's siblings, grandparents, other family members, important other adults or neighbors, care providers.... anyone in your child's life on a regular basis.

Before the IFSP is developed, you will determine the natural setting for services for your family and child. You make this decision based upon a variety of information and your personal lives. You may select several locations depending upon the outcomes in the IFSP and your own schedules and other commitments.

By providing services and supports within the daily routines and activities of your child including those people and places in your life it is hopeful that:

- You and your child can participate in early intervention with as little disruption to your life as possible;
- That your child will feel comfortable while receiving early intervention services;
- That by providing services in a place that your child interacts normally, your child will be able to use the skills in their everyday routine; and
- That by including the people in your child's life, they will have an increased knowledge of how your child learns.

At the IFSP Meeting

Working on the IFSP is a team effort! You, your intake coordinator, the providers who participated in the evaluation and other participants will:

There are 16 services that have been identified as early intervention services:

- Assistive Technology
 - Audiology
 - Family Training
 - Health Services
 - Medical Service*
 - Nursing Services
 - Nutrition Services
 - Occupational Therapy
 - Physical Therapy
 - Psychological Services
 - Service Coordination
 - Social Work
 - Special Instruction
 - Speech Therapy
 - Transportation
 - Vision Services
- (*For diagnostic purposes only)*

Things to consider when planning for services

- *What activities do you want your child to achieve over the next 6 months to a year.*
- *What does your current schedule look like and what are good times for services to occur.*
- *Does your child have any special needs that a provider should specialize in?*
- *Where does your child practice the skills that you would like to see improved?*
- *How much work (therapy) can your child participate in at one time.*
- *What times are good for your child? (Take into consideration nap times, lunch.... Morning, afternoon...)*
- *How involved do you or your family want to be involved in the services provided. Do you want exercises that you can do at home?*

Your family's IFSP will include the following information:

- *A statement of your child's present level of functioning.*
- *With your permission, a statement of your family's resources, priorities and concerns related to your child's development.*
- *A statement of the major outcomes expected from early intervention services.*
- *A statement of the early intervention services, needed to meet your child and family's needs.*
- *A statement of the natural environments where early intervention services will be provided.*
- *A statement about other services, including medical services, that are needed by your child and family that are not provided by First Steps.*
- *The projected dates that services will begin and the period of time during which services will be delivered.*
- *The name of the ongoing service coordinator and the other providers that you have chosen to work with your family.*
- *The type and amount of services that your child will receive.*
- *Information regarding transitions or changes that you may expect during the time that your child is within First Steps.*

- Review the information that has been gathered about your child;
- Talk about your family's resources, priorities, and concerns;
- Identify the outcomes - or progress - expected for your child and family from early intervention services; and
- Identify strategies, activities, and services that will lead to the outcomes you hope to reach.

You have the right to say yes or no to any of the services talked about at your IFSP meeting. To include a service in your IFSP, you and the IFSP team must agree to the service.

If you disagree with the decision of the IFSP team about an early intervention service you may ask for mediation and/or impartial hearing to settle your differences. In the meantime, the early intervention services you and the team agree upon will be provided.

You will be asked to sign your IFSP when the plan is finished. Participating in the First Steps program is voluntary. When you sign the IFSP, you show that you were at the IFSP meeting and that you agree to the services in the plan. You are also giving your permission to start early intervention services.

The IFSP is an important document! If you need extra time to think about the plan, ask for it. You may want to discuss the plan with other family members or review it to make sure it meets the needs of your child and family.

PUTTING YOUR IFSP INTO ACTION

Putting your IFSP into action is a team effort! You and your family are important members of the team. Be a part of your child's services. You can do this by:

- Arranging services at times that will allow your participation.
- Asking providers working with your child to teach you the skills you need to help your child make progress.
- Keeping notes, a diary or a journal about how services are working and how well your child is doing. Think about what is and what is not working. Ask for a change in services if you think a change is needed.

Your IFSP is written for one year. During the year there are many times when the plan should be reviewed and even changed.

Reviewing, evaluating and changing the IFSP

As your child grows and changes, so will the early intervention needs of your family. To be sure your IFSP keeps pace with your family and stays

useful, the First Steps system requires:

- Six-month reviews of the IFSP.
- Annual meeting to evaluate the IFSP.
- A process for changing the IFSP between six month reviews and annual meetings.

The six month review and annual meeting to evaluate the IFSP are designed to make sure that the IFSP still makes sense for your child and family. You and the other participants will look at how well early intervention services have helped your child and family meet the outcomes in your IFSP. You will also talk about what should be changed in the IFSP. This may include:

- Adding new outcomes and dropping old ones that have been reached, or that are no longer important.
- Changing strategies and activities to help meet new outcomes or outcomes that have not yet been reached.
- Changing the services needed by your child and family.

Just like when your first IFSP was developed, the team must come to agreement on the services that your child should receive. You will be asked to sign the IFSP and any changes, giving your permission for services to take place. If you do not agree with the services listed in the IFSP you have the right to file an appeal with your Service Coordinator and the Bureau of Child Development.

You can request a review of your IFSP at any time. Your ongoing service coordinator can set up the meeting whenever one is needed.

Payment of Services

Evaluation and assessment, as well as service coordination are provided at no cost to families. Other developmental services are provided through a cost-sharing program with families, based on a family's income and the number of people living in the home. This "sliding fee" will be explained to you by your intake coordinator who has information that makes it easy to understand.

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Your ongoing service coordinator is responsible for making sure the IFSP is reviewed and evaluated on time. The people who are involved in this process are:

- *You and anyone you ask to participate;*
- *Your ongoing service coordinator*
- *The providers who are providing services to your child and family;*
- *Other persons invited by your service coordinator with your agreement; and*
- *A family advocate at your request.*

TRANSITION

Your child's transition plan will include:

- *Steps needed to help your child get used to and get along in a new setting.*
- *Steps in identifying programs or activities that your child may transition into.*
- *Timelines and persons responsible to make referrals or get program information.*
- *Tentative dates for transition meeting or time to meet other persons involved in the transition.*

During your participation in the First Steps program your child may go through several transitions. Children transition out of hospitals, change service providers and location of service, your family may move from one city to another. All of these transitions or changes may be addressed within your IFSP. Your ongoing service coordinator will help your family with the changes to ensure that services are provided smoothly.

Although all children's experience within First Steps may be different, all children will participate in the transition out of the First Steps program. This may be a scary time for families as it is a big change. The service coordinator will assist the family in identifying services that the child may need as she or he exits the system. Some children may no longer need services. Other children and families may go on to early childhood programs in the community. Some children in the First Steps program will be eligible for preschool special education services within their school districts.

Every child must have a transition plan developed and written into the IFSP outlining the steps to transition. Usually, this plan is developed at an IFSP meeting prior to your child turning two and half years old. However, this transition may occur at any time during a child's First Steps experience depending upon the progress of each individual child. Your service coordinator will also work with you to better understand what your rights are and what should happen when your child leaves the First Steps program. Your service coordinator will help you become an advocate for your child.