



First Steps

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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Welcome to First Steps.

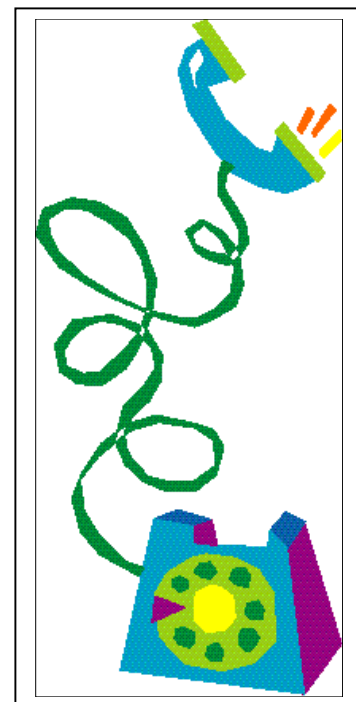
The purpose of this handbook is to provide an explanation of the First Steps Early Intervention System. Your child has been referred to your local First Steps System Point of Entry (SPOE) because of a concern about your child's developmental progress. This handbook will help you understand all of the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

One of the underlying values of the First Steps System is family choice. Included in this handbook is a section developed by other families that contains key questions that you need to ask when you select your service providers.

We have also included a section of commonly used abbreviations in First Steps. This will help you understand some of the jargon that is used by providers.

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

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.

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.*
- *Consent for assessment if one is needed.*
- *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.*

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 20% in one developmental area or 15% delay in two or more developmental areas; or*
- *A biological risk factor that has a high probability of leading to a developmental delay.*

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. This is typically true if a child has a biological risk factor but is displaying skills typical of the child's same age peers. 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 how 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

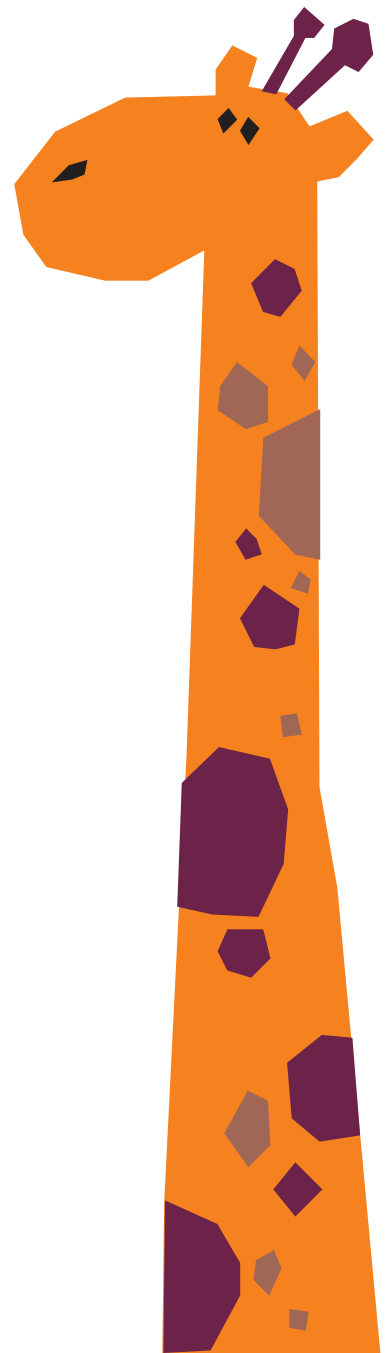
Every family is different. You know your family best - and what you can do to help your child's development. You know what is most important to you, your child, and family - and what concerns you most.

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;



- 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.

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

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

First Steps services are provided at no cost to families. Families will however receive information on the payment of services on their behalf. This information will come to you through the mail in a statement called an **explanation of benefits (EOB)**.

As soon as your child begins to receive First Steps services, you will receive these notices in the mail. This mail will come to you from the state's billing agency, the Central Reimbursement Office (CRO). This is the agency that will make payments to the providers working with your child. In order to keep families informed about the services that the State of Indiana is paying for, you will receive these notices for all of the services that your child receives through First Steps. The EOB will be mailed to the family and will include information regarding the type of service, the amount billed for and the amount of money paid. For all providers except service coordinators, First Steps reimburses for the face to face time contact they have with you or your child. Please

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.*

remember, this is **not a bill**. When you receive a statement, you should review the information. A sample EOB is included in the appendix. If you have any questions about the sample form, or an actual form that you receive in the mail, please talk to your service coordinator.

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.

Appendix A
Description of First Steps Providers and Services

FIRST STEPS PROVIDERS

Each family in the First Steps system is provided with a team of specialists who work with them. Each team should look a little different, depending upon the needs of the child, and the priorities of the family. As you think about who should be on your team, consider your concerns and priorities for your family and your child. Work with your Intake Coordinator to identify specialists who will be able to address these issues with you.

The following are descriptions about various professionals in early intervention and what their area of specialization is.

The Service Coordinator

A Service Coordinator is an individual on your early intervention team who will work with and for you and your family. With the assistance of your Service Coordinator through the IFSP Team process, together you will develop outcomes, identify appropriate services and coordinate these with you and other professionals. Together, you and the Service Coordinator work to monitor, review and evaluate your family's Individualized Family Service Plan (IFSP). You and the Service Coordinator plan together as your child approaches transitions to different services, providers or settings.

Your Service Coordinator has experience working with families of children with special needs. Service Coordinators have knowledge of early childhood development, and understand the local early intervention service system. Your Service Coordinator works with you to ensure that you understand your procedural safeguards, and that you are an active participant in all of the planning, review and service selections that occur for your child and family.

One of the key outcomes in service coordination is to ensure that each legal guardian/parent is well informed of their rights, opportunities and responsibilities and that you gradually assume more of these advocacy, planning and coordinating activities on your own. Together, you and your Service Coordinator will define individual needs for service coordination and plan these activities in a way that is family-centered and supportive to your family's schedule and lifestyle. In the First Steps early intervention system, you will initially have an Intake Coordinator who meets the same level of qualifications, background and experience as a Service Coordinator and is responsible to assist you in the eligibility determination. If so, planning will begin for the initial IFSP development activities. The Intake Coordinator will also discuss the importance of ongoing service coordination. You will make a selection of a local Service Coordinator to work with you as you participate in the First Steps system.

Service coordination is the only one, consistent service that ALL families with a child eligible for early intervention receive.

Your service coordinator is responsible for:

- *Helping you obtain the services you need.*
- *Coordinating early intervention services with other services your family is getting.*
- *Making sure your child and family get all the services in your IFSP.*
- *Making sure services are delivered on time.*
- *Helping you find service providers.*
- *Informing you about advocacy services.*
- *Making sure six month reviews and annual evaluations of your IFSP are completed.*
- *Helping you make any changes to your IFSP that may be needed between the six month reviews and annual evaluations.*

You will select the Service Coordinator once your child is determined eligible for First Steps. This individual works together with you and the Intake Coordinator as the first IFSP is developed. From that point on, the Service Coordinator is the lead team member that you should rely upon for problem solving, assistance and IFSP activities. If you feel that your Service Coordinator or any other early intervention professional isn't meeting your needs, you may request a different provider at any point in time.

Your Service Coordinator will assist you in reviewing and making informed decisions about financing services for your child and family. This includes understanding your private health insurance coverage or Medicaid benefits plan. Your Service Coordinator may also assist you in arranging for various assessments or evaluations for your child. Your Service Coordinator will also work with you to identify and schedule your family's IFSP team. Your Service Coordinator will also have a copy of your county's local Service Matrix that details the providers available to serve you and your child, and to monitor these services through the IFSP with you. They can also help you get linked with other parents or parent support groups, advocacy organizations or other information sources that you identify as important to your family.

Finally, your Service Coordinator works closely with you to identify planning needs for various transitions that may affect services for your child and family. These transitions include consideration of medical or surgical appointments that your child has. It could also include family events such as the birth of new baby or employment changes. Service delivery changes such as moving from home to a center-based program or transition as your child leaves the First Steps system are other times your Service Coordinator can provide you with assistance.

Some children will be eligible for other state-sponsored programs that also provide some sort of service coordination or care coordination. Each of these programs has a little different focus and, as a result, their service/care coordinators may have different skills and abilities than a First Steps Service Coordinator. Some of these skills may be more appropriate to your needs. The goal of each program is that you have the support and assistance you need. Several CSHCS and Healthy Families service/care coordinators are also credentialed as First Steps Service Coordinators. This is so they can help you with both programs. Sometimes it is more appropriate to have two Service/Care Coordinators -- one who you identify as the "lead" coordinator who works with support and back-up from the shadowing Service/Care Coordinator. You will discuss these issues with your First Steps Service Coordinator and make sure that these arrangements are spelled out in your child's IFSP.

The Physician

Children who enroll in First Steps must have a primary care physician. This may be a pediatrician or a family practice physician. The Physician will assess your child's health, growth and development. They will coordinate various medical evaluation services for your child and provide follow-up medical care. Diagnosis and treatment may involve consultation with other medical pediatric specialists. Your child's "medical home" should coordinate these medical consultations and interpret the results to you. The Physician is responsible for guiding you to services that may help you with your child's medical problems. These could include:

- Ophthalmologists - specialists in eye conditions
- Otolaryngologists - ear, nose, and throat specialists
- Orthopedists - bone specialists
- Neurologists - specialists in the functioning of the nervous system
- Geneticists - specialists in hereditary conditions
- Rehabilitation specialists - experts in the medical care of children with chronic health conditions
- Cardiologists - specialists in heart conditions
- Endocrinologists - specialists in glandular functions

The Physician may consult with other service providers and maintain regular contact with you. They will talk with you about your child's condition, explain how your child's medical problems may affect his/her functioning and what these problems might mean for the future. Depending upon your child's individual needs and the medical services available within your community, you may actually use a Family Practice Physician for pediatric care for your child. In either case, the Pediatrician or the Family Practice Physician serves as your child's "medical home" or "primary care physician" and is an important member of your IFSP Team.

Medical Services include limited testing and consultations that are required to either determine your child's eligibility or to assist in IFSP development. The First Steps system is not responsible for regular well child care, immunizations or medical services including surgery or prescriptions. Families may access these services through their private health coverage, Hoosier Healthwise, Children's Special Health Care Services (CSHCS), Maternal and Child Health projects (MCH) or local clinics or health department services.

First Steps requires that each child enrolled for early intervention services have a primary medical care home. Depending upon your child's individual needs and the medical services available within your community, you may have a Pediatrician or a Family Practice Physician for pediatric care for your child. This individual serves as your child's "medical home" or "primary care physician" and is an important member of your IFSP Team. A major role of the medical home provider is to coordinate all of the specialty care that a child receives, as well as to make sure that routine well child care visits and immunizations happen on schedule.

Any provider of First Steps early intervention services may assist the IFSP team to recommend and obtain assistive technology devices for your child, based upon his/her needs.

Assistive Technology Devices and Services

Assistive technology (AT) includes a variety of items, equipment or materials. AT is used with individual children to increase, maintain or improve their functional capabilities. Assistive technology ranges from orthotics, to specially adapted toothbrushes, to specially designed devices to assist with a child's hearing or vision, eating utensils, specialized feeding chairs and positioning aides such as bolsters and wedges. These needs may be short-term in nature (such as a bathing support), or more long term devices such as wheelchairs or hearing aides. Assistive technology can also include adaptations made to toys and learning materials that permit your child to be more successful in their play and developmental activities.

The Audiologist

The Audiologist is concerned with your child's hearing, and works closely with a Speech/Language Pathologist to find out if there are communication problems and plan for their improvement.

An Audiologist will test your child's ability to hear different sounds. They can determine through a variety of tests if your child has a hearing loss and what the degree of this loss may be.

An Audiologist will test your child's ability to hear different sounds. They can determine through a variety of testing approaches if your child has a hearing loss and what the degree of this loss may be. If your child has a hearing disability, the Audiologist will look for reasons for the hearing loss. They may be able to explain how your child's hearing is likely to progress. The Audiologist may recommend special communication aides for your child. You will learn how to operate this equipment and get help to maintain this equipment in good use for your child. This specialist can also talk with you about how to manage your child's hearing problem, and how to communicate with your child.

Audiological Services can identify if your child has a hearing loss, how significant this loss is and what it means for your child's communication and general development. Audiological services also include training your child in specific ways of communication, fitting your child's with aides to help them hear or communicate better, and to maintain the devices in good working order and make sure that you know how to operate and care for this equipment.

The Developmental Therapist is trained in infant/toddler development and ways to promote learning and development. This area of child development is called "cognition" or cognitive development.

The Developmental Therapist (Special Educator)

Your child's early learning experiences are critical for his or her future development. The Developmental Therapist is trained in infant/toddler development and ways of promoting learning and development. This area of child development is termed "cognition" or cognitive development. This specialist understands the implications of disability or developmental delay upon the normal progression of development. They are skilled in working with families of children with special needs. They

work closely with other specialists to ensure that comprehensive early intervention services are provided.

This professional will work with your family to help your child develop the skills needed for learning. They can help you monitor your child's developmental milestones. The Developmental Therapist looks at how your child understands the environment. During an assessment, the Developmental Therapist observes your child's learning style, communication, and social skills. This professional will talk with you about activities that you and your child can do together, and will help develop a series of developmental activities that encourage your child to actively explore the environment.

Developmental Therapy or Special Instruction includes designing learning environments and activities to meet the individual developmental needs of your child. This service should include working with you to develop activities that will promote development in your child that you and other caregivers can do throughout the day with your child.

Health Service Providers

Health services are provided to eligible children so that the child will benefit from other IFSP services. They are provided during the time that other EI services are being provided. Health services would include services such as clean intermittent catheterization, tracheostomy care, tube feeding, the changing of dressings or colostomy collection bags, and other health services. Individuals performing these services for your child must be trained and supervised by another health professional, usually a nurse or physician.

Health services also include helping your child's physician work with other service providers concerning the special health care needs of your child. These all need to be addressed in the course of providing early intervention services, and in monitoring these services.

The Nurse

The Nurse is responsible for assessing the health of your child and family. A Nurse may also provide nursing care to prevent and improve health problems related to your child's disability. The Nurse works with you to promote the best possible health for your family and for the development of your child. The Nurse may ask you about your child's general health, medications, eating habits, bowel and bladder functioning, exercise and sleep patterns. The Nurse will assess your child's growth and development from this and other information.

Nursing services are individual interventions conducted with the child and/or family that support the other early intervention services. These services ensure that the medical and health needs of your child are

Health services may be necessary to enable a child to benefit from other early intervention services during the time the child is receiving the other early intervention services.

Nursing Services are individual interventions conducted with the child an/or family that support the other early intervention services and ensure that the medical and health needs of your child are included in your child's IFSP as appropriate

The Nutritionist is concerned with your child's food and nutritional requirements for good health.

included in your child's IFSP as appropriate. The nurse may help you to plan and carry out the medical treatments to aid your child's development. A nurse may provide information about child rearing or health issues, or about ways to cope with your child's disabilities. Finally, a nurse may assist you in obtaining any health services you need.

The Nutritionist

Good nourishment will help your child to benefit more from other services in the IFSP. The Nutritionist knows about the content of foods and can help you plan a special diet, if needed. The Nutritionists can make nutritional modifications and recommend foods and textures depending upon your child's special needs and feeding concerns.

The Nutritionist may assess your child's eating habits and feeding skills, to determine how these may affect your child's growth. The Nutritionist can help you to develop a menu plan, and will work with you to use this plan. The Nutritionist can advise you about budgeting and food selection, taking into account your family's financial situation and time limits. The Nutritionist works closely with you, your physician and other members of the IFSP team to coordinate nutritional activities with all other services that your child and/or family may be receiving.

Nutrition services under the First Steps system focuses on your child's specific nutritional needs, including the development of a nutrition plan that is individualized according to your child's disability. Nutrition services also help you to access other community services to carry out your nutritional outcomes. Many times, families with children enrolled in First Steps will also be eligible for the Women, Infant and Children's nutritional program, or WIC. The WIC program provides nutrition services that may also address the specific nutrition issues that your child has due to their disability as well as general nutrition and feeding issues.

The Occupational Therapist helps your child master basic skills for daily living and independence. These areas are termed "fine motor" and "adaptive" skills.

The Occupational Therapist

This professional designs activities with you and your child which will develop adaptive skills such as feeding, walking and certain physical movements. The term "adaptive" includes activities such as toilet training, dressing and other self-care activities. The Occupational Therapist will also focus on your child's "fine motor" skills. Fine motor activities include feeding, play with small toys and finger and hand games that lead to pre-writing skills.

An Occupational Therapist will identify your child's strengths while noting the challenges that your child faces in carrying out daily tasks. Another way to look at this is that the occupational therapist will look at three things. First, what specific skills does your child have? Second,

what is the quality of these skills? Third, how much control and intent does your child have of their skills? The therapist may observe your daily routines with your child. You may be asked about your child's responses to various situations and how your child interacts with the family.

The Occupational Therapist may select or design special devices that will help your child develop the skills he or she needs. The therapist may suggest things to prevent or minimize the effects of a disability or developmental delay. The therapist will also suggest activities and tasks for you to do with your child in the normal course of your child's day. They will also work with other professionals or caregivers to share and monitor these activities.

Occupational therapy helps to develop adaptive or physical skills that will aid your child in their daily living and improve interactions with your child's physical and social world. Occupational therapy focuses on developing skills related to sensory-motor integration, coordination of movement, fine motor skills, self- help skills (feeding, dressing) and may include various adaptive devices or equipment that help your child in these activities.

The Physical Therapist

The Physical Therapist may assess your child's motor or movement skills by watching your child at play or doing an activity. The Physical Therapist will plan a therapeutic exercise program together with your family that is enjoyable for both you and your child. The therapist may recommend or make special equipment and mobility devices or have these made. You will be provided with advice about adapting toys or play equipment and about other physical aids for your child. He/she may also recommend ways of modifying your home to help you care for your child, and may be able to help you in making these changes if you wish. The Physical Therapist is also able to teach you new techniques for physically handling and positioning your child.

Both the Physical Therapist and the Occupational Therapist are concerned with children's physical abilities. However, the Physical Therapist focuses on your child's gross motor skills or ability to move and effectively use his/her legs, arms and head. The Occupational Therapist usually focuses more on your child's fine motor skills. These are skills that your child uses to respond to what he/she sees, hears, feels, tastes, or smells by using his/her hands, fingers and mouth.

Physical Therapy services focus on instructional support and treatment of your child's physical disabilities that helps your child to improve the use of their bones, muscles, joints and nerves.

The Physical Therapist focuses on your child's gross motor skills or the ability to move and effectively use his/her legs, arms and head.

The Psychologist

The Psychologist is concerned with your child's learning and social and emotional development. He/she may assess your child's developmental progress and provide recommendations for treatment or services. If assessing your child, the Psychologist will observe your child's behavior, and may carry out some psychological tests. These may be done with your family present so that you can explain how your child typically behaves.

The Psychologist is concerned with your child's learning and social/emotional development. Psychological services primarily focus on working with problems in a child and family's living situation, which affect the child's utilization of early intervention services.

After an assessment, the Psychologist provides information about your child's general functioning and social skills. The Psychologist can help you and others with managing your child's behavior. This professional can recommend games you can play and activities to do with your child to help him/her develop and learn.

The focus of **psychological services** is to work with problems in your living situation, which affect the child's utilization of early intervention services. This service may include the administration of psychological or developmental tests with your child. This may include other assessment procedures and interpreting these assessment results. The Psychologist may also show you how information about your child's behavior relates to learning, mental health and development. This professional can also plan and manage a program of psychological services. These services may include psychological counseling for your child and family, family counseling or consultation on child development, parent training and education programs specific to your child's developmental needs.

The Social Worker

Social Workers provide family counseling, work with parent groups, coordinate services, and help to link families to other community resources and services.

Social workers help with those concerns that relate to the developmental or special needs of your young child, and your family's ability to meet the needs of your child given these circumstances. A Social Worker is concerned with supporting your family and helping you to resolve any difficulties or concerns that are preventing or interfering with the ability of your child and/or family to participate in early intervention services. Social Workers provide family counseling, work with parent groups, coordinate services and can help link you with other community resources and services.

The Social Worker will want to hear about what you see as your child's strengths and needs and your goals for your child. The Social Worker may talk with you about your child and any difficulties that you may be having in relation to your child. He/she may suggest changes that might improve your family's situation, as well as how each family member can help in the care of your child. Together you and the Social Worker will identify family members, friends, and community resources that are available to assist and support you in caring for your child.

The Social Worker may also help your family locate community services to meet your basic needs. The Social Worker may also provide counseling services related to your child's ability to utilize early intervention services. This professional may be able to link you with support groups for parents and support services such as respite care or child care.

Social work services support your family so that you can provide an optimum environment for your child.

The Speech/Language Pathologist

The Speech/Language Pathologist is concerned with promoting your child's communication skills, focusing on difficulties with speech or language. This professional looks for early signs of communication problems. Communication development occurs in two primary ways -- receptive and expressive skills. "Receptive" skills are related to what your child can understand. "Expressive" skills are your child's way of communicating with you -- quieting to familiar voice sounds, smiling, babbling, eye contact, pointing, simple phrases or sentences.

If you or someone else is concerned about your child's speech and/or language, the Speech/Language Pathologist can assess your child's language development and his/her ability to communicate. These findings will be shared with you and should be considered as your team develops IFSP outcomes. You should be involved with your child's therapy plan in an active way. The Speech/Language Pathologist will reassess your child's level of communication from time to time. This professional will consult with you and the other team members to help your child continue to develop his/her own communications skills. This may include the use of alternative communication approaches, such as American Sign Language, total communication or oral communication approaches. It might also include assistive technology such as hearing aides and other adaptive equipment devices.

Speech and language therapy services for your infant or toddler primarily focus on instructional support for your child, your family and other caregivers to enhance your child to communicate including all of the developmental skills that happen before your child actually "talks". If your child has a hearing loss, these services can include helping you to obtain and use various devices to help your child hear and communicate.

Transportation

Transportation services make it possible for your child and family to participate in activities related to early intervention services. Transportation services may be used for assessment and evaluation services for eligibility determination and/or IFSP development. It also includes transportation necessary for your child to receive early intervention services addressed in the IFSP.

*Communication development occurs in two primary ways: **receptive skills**- what your child understands- and **expressive skills** – your child's ability to communicate with you in a variety of ways.*

Transportation services may include reimbursement for mileage and related costs to the family member OR to a private or public source of transportation selected by the family.

Transportation services include the cost of travel (mileage, parking fees, taxi or bus) and other supports that are necessary for your child and family to receive early intervention services.

Vision Services

Vision Services include the evaluation and assessment of visual functioning as well as diagnosis of visual disorders, delays and abilities. Vision services also include referral for professional treatment, communication skills training and mobility training, including independent living skills. A licensed physician called an Ophthalmologist may provide these diagnostic services. For children with visual impairments, professionals specially trained in mobility (getting around safely and independently) may work with your child. These professionals are called "Orientation and Mobility Specialists". Often these specialists work with you in your home or other locations where your child spends time. This specialist makes certain that the environment is structured appropriately for your child and that he/she is learning to use any assistive technology devices that have been obtained for them. The mobility specialist will coordinate these activities with other professionals serving your child as well as your child's primary care physician.

Vision services focus primarily upon the identification of specific vision impairments, delays or abilities that affect your child's overall development. It does not include routine eye examinations or glasses that are for the sole purpose of correcting your child's vision.

For children with visual impairments, professionals specially trained in mobility (getting around safely and independently) may work with your child.

Appendix B
Guide to Selecting Your Child's Provider

SELECTING YOUR CHILD'S PROVIDERS

Before choosing service providers, think about what is important to your family. The following is a list of questions/considerations developed by other families that you may find helpful. Consider what you need for yourself, your child and your family and what you want from a provider. The questions listed may suggest other questions you want to ask. Take your list to your meeting with your service coordinator to help you when selecting a provider.

Thinking through my family's wants and needs:

- What does my family do or enjoy that we want to continue after beginning First Steps?
- What, if anything, are we willing to give up to fit services into our family life?
- What things are important for our child and our family in the next 6 months? one year? five years?
- How does our family react to challenges?
- What strengths do we bring to new situations?
- How are decisions made in our family?
- Who can we depend on for support (friends, family, church members)?

Thinking through what we need from a team member:

- Do we prefer a new graduate who may have new ideas or someone with years of experience in their field?
- When will services best fit into our schedule? How and where will services best fit our needs?
- Do we prefer someone business like or who feels more like family?
- How do we want a provider to respond if our child cries or doesn't want to work?

INTERVIEWING POTENTIAL PROVIDERS

Before you choose a service provider, it is important to talk with providers who can be there when and where you need them. Your planning team can give you names and telephone numbers of providers who meet your needs. You should feel free to call and speak to as many as you wish before making a decision. You may want to look at the following questions and mark those that are important to you before calling a provider. When you call, be sure to discuss your child's condition and needs.

As you decide when and where services best fit into your schedule, keep the following in mind for planning purposes:

- ✓ *Work schedules of family members.*
- ✓ *Scheduled activities of children including school, sports, music or dance lessons and other activities.*
- ✓ *Regularly scheduled appointments*
- ✓ *Schedule for church, clubs, organizations, committees and other social events.*
- ✓ ***Remember to block out personal time.***

Parental involvement as a team member

- ✓ *Communicate your goals for your child*
- ✓ *Consider short term goals (next 3 months) and long term goals (next 3 years)*
- ✓ *Use IFSP as a guide, but it can always be changed*
- ✓ *Attend therapy when possible and devise ongoing communication system with providers and other caregivers*
- ✓ *Follow through with suggested therapy regimen between visits*
- ✓ *Be sure providers communicate with each other*
- ✓ *Communicate any problems and concerns early – don't wait until it's a big deal*
- ✓ *Communicate family transitions with your team members (marriage, death, divorce)*

Provider Profile

- What is your educational background?
- What experience do you have with children age 0 to 3?
- Why did you choose your job?
- Are you a family member of a person with special needs?
- Are you a member of a professional organization?

Philosophy

- How do you involve families in reaching goals for their child?
- How do you deal with conflict if we don't agree?
- How do you work with a crying child? How do you work with a stubborn child?
- Will you give us activities to follow through with therapy at home?
- How will you teach us to work with our child between visits?
- Will you teach other caregivers such as grandparents or daycare providers?
- Will you give us a plan to follow at home?
- How do you share information with family members and service providers?
- What techniques do you use during your visits?
- What equipment do you use during your visits?

SPECIAL CRITERIA

- What hours and days are you available?
- Do you have an opening to take our child now?
- How flexible are you with schedules? (Can you come at 9:00 a.m. this week and 10:00 a.m. next?)
- Are you available between visits if we have concerns or questions?
- Will you work in homes, preschools or other places our child may be? (Will you come to my child's grandparents' home for visits?)
- With the family's permission, can we talk to other families with whom you have worked?
- Can we watch you work with another child (with the permission of the parents)?
- Have you ever worked with our child's disability or something similar?
- Are you able to help us select equipment and materials if needed (wheelchairs, communication boards, etc.)?
- Have you worked with medically fragile children?
- Are you able to continue to provide service to my child after First Steps if necessary? If so, how are fees handled?

Appendix C

A Dictionary of Abbreviations

AAP	American Academy of Pediatrics
ADA	Americans with Disabilities Act
ARC	Association for Retarded Citizens
BCD	Bureau of Child Development
CCRR	Child Care Resource and Referral
COTA	Certified Occupational Therapy Assistant
CPS	Child Protective Services
CRO	Central Reimbursement Office
CSHCS	Children's Special Health Care Services
DFC	Division of Family and Children
DOE	Department of Education
DT	Developmental Therapist
EI	Early Intervention
EOB	Explanation of Benefit
FERPA	Family Educational Rights and Privacy Act
FCM	Financial Case Management
FSSA	Family and Social Services Administration
HMO	Health Maintenance Organization
ICC	Governor's Interagency Coordinating Council
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Plan
IFSP	Individualized Family Service Plan
ISDH	Indiana State Department of Health
LPCC	Local Planning and Coordinating Council

LRE	Least Restrictive Environment
MCH	Maternal and Child Health
NICU	Neonatal Intensive Care Unit
OFC	Office of Family and Children
OSEP	Office of Special Education Programs
OT	Occupational Therapist
PA	Prior Authorization
PT	Physical Therapist
PTA	Physical Therapy Assistant
SLP	Speech Language Pathologist
SPOE	System Point of Entry
SSI	Social Security Income
TANF	Temporary Assistance to Needy Families
WIC	Women, Infants and Children Nutrition Program

APPENDIX D
Sample Explanation of Benefit

Central Reimbursement Office
 c/o PDA Software Services, Inc.
 PO Box 29134
 Shawnee Mission, KS 66201-9134



EXPLANATION OF BENEFITS

Client ID No.	Client's Name	Dates
9901-00160	TAMRA M. SMITH	07/01 /01 To 7/31/01

This is NOT a bill.

DAVID SMITH
 615 N ARLINGTON AVE
 SOUTH BEND, IN 46601

For inquiries regarding information
PDA at 1-888-567-2351

Claim No. Provider Name Service Category	Service Dates	Statement Date	Amount Billed	Amount Denied	Amount Disallowed	Amount Paid
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Claim: 010716-21-05
Provider: SUE ANN BRUMLEY

Occupational Ther.	03/01/01		30.00	5.06	0.00	24.94
Occupational Ther.	03/08/01		<u>30.00</u>	<u>5.06</u>	<u>0.00</u>	<u>24.94</u>
		07/16/2001	\$60.00	\$10.12	\$0.00	\$49.88

ClaimNote Charges exceed program allowance

Claim: 010724-21-235
Provider: JONATHON SMITHERS

Service Coordination	06/29/01		<u>52.27</u>	<u>00.00</u>	<u>00.00</u>	<u>52.27</u>
		07/24/2001	\$52.27	\$0.00	\$0.00	\$52.27

Benefit Totals:			\$112.27	\$10.12	\$0.00	\$102.15
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