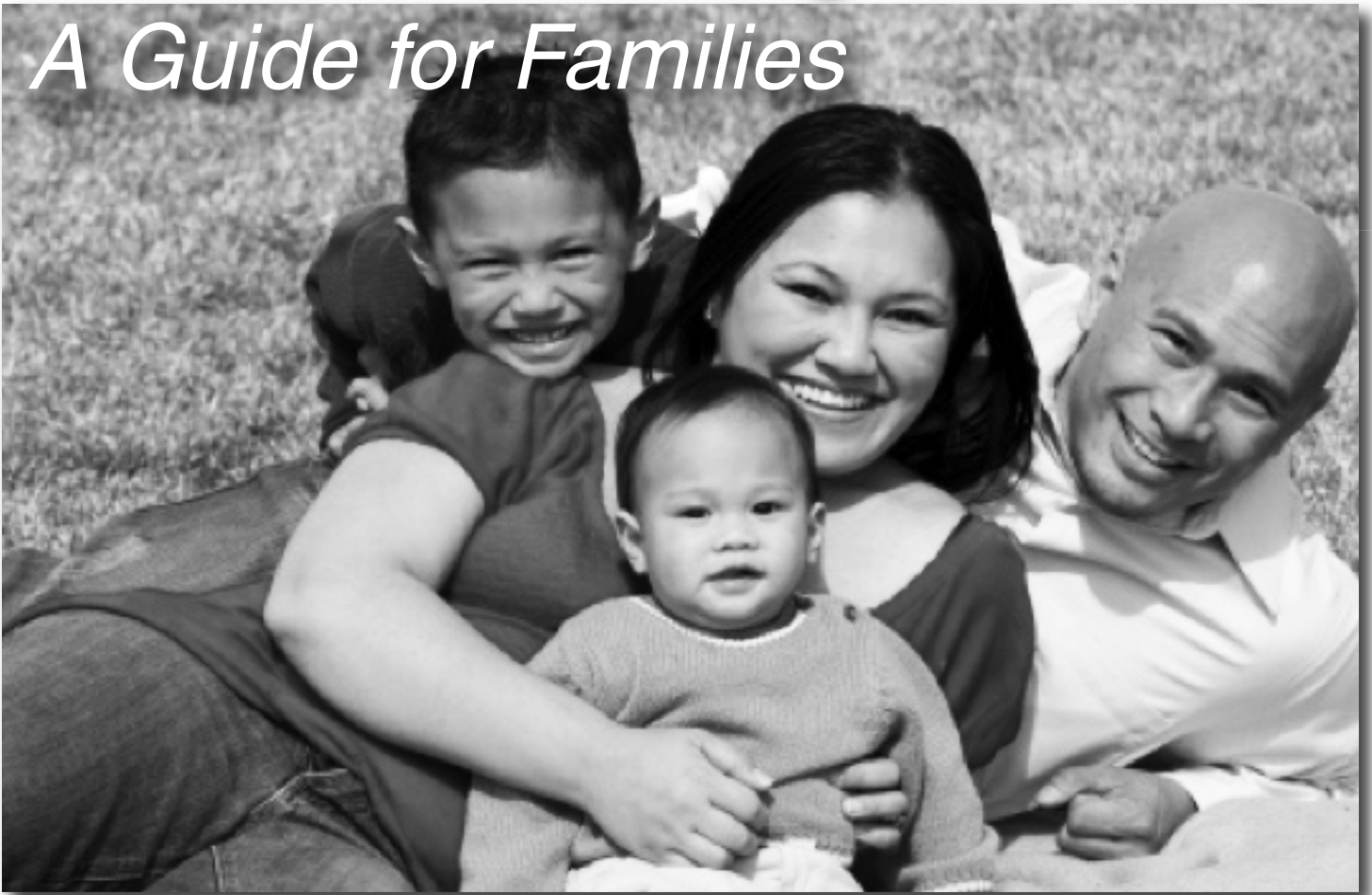




The Illinois Early Intervention Program:

A Guide for Families



March 2011



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March 2011

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Please note that the guide uses the phrase “your child” when conveying information about early intervention services and programs. The worksheets in the back of the guide shift to “my child” when families are invited to complete forms to share information about themselves. We wish all families success on their journey through the first three years of their young child’s life. We hope that this guide provides help as you move through the Illinois Early Intervention Program.

Susan A. Fowler, Director
Illinois Early Intervention Clearinghouse

Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof, or many. A family can be as temporary as a few weeks, or as permanent as forever. We become a part of a family by birth, adoption, marriage, or from desire for mutual support. A family is a culture unto itself, with different values and unique ways of realizing its dreams; together our families become the source of our rich cultural heritage and spiritual diversity. Our families create neighborhoods, communities, states, and nations.

(Source: *Report of the House Memorial 5 Task Force on Young Children and Families*, 1990, New Mexico)

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I. Welcome to the Illinois Early Intervention Program!

Do you have questions or concerns about your baby or toddler? Do you wonder if your child's development is on target for her age? Most delays are nothing to worry about, but in some young children, delays can signal a special need. This guide is written for families with questions about their infant or toddler's development.

About 18,000 families are enrolled in the **Illinois Early Intervention (EI) Program** at any point in time. *The Illinois Early Intervention Program: A Guide for Families* explains the EI Program. It describes EI services and who may qualify for these services. The guide describes how you can request an evaluation for services. It describes your role in planning services and as a member of your child's team. It also discusses your legal rights and answers questions that many families ask. Appendix A is a glossary that lists and defines many of the terms used in EI. Words in bold in this guide are included in the glossary.

We hope the guide will answer your questions and help you make decisions that will give you and your child a good start. In Illinois, EI services are provided in your local community. Each county is served by one of 25 **Child and Family Connections (CFC)** offices. For more information or to make a referral to the EI Program, call your local CFC office. For the number in your area, call 1-800-323-4769 or 1-888-594-8364.



Parenting my premature baby was wonderful and challenging at the same time. My early intervention team helped me find more of the 'wonderful' in being a parent by showing me different ways to help my baby move and play and eat and sleep. My confidence grew by miles, as my baby grew by inches and pounds, thanks to their support!



What is the Illinois Early Intervention Program?

The Illinois Early Intervention (EI) Program provides a variety of services for families of an infant or toddler with a disability or a developmental delay. In some cases, the program also helps families with very young

children who are at risk of being delayed. The program is based on the idea that all families help their children learn and grow. Families with a child with special needs may need support to figure out the best ways to help their child develop. Families are partners with professionals in the EI Program to help their child have the best start in life.

Your infant or toddler (birth through 36 months) is eligible for services through the Illinois EI Program if he or she

- has a significant delay in at least one area of development,
- has a condition that is known to cause disability or delay, or
- is at high risk for a developmental disability.

These offices are a family's first stop for questions about EI services. The CFC staff can answer your questions about your child's development. They can help you decide if your child might benefit from an evaluation. They can arrange for children under the age of 3 to have evaluations and **assessments at no cost to the family.**



If your child qualifies for the EI Program, a team of **EI providers** and your CFC **service coordinator** will work with you to design a service plan, also at no cost. The plan is called the **Individualized Family Service Plan (IFSP)**. It is used to identify your priorities for your child and important outcomes for your child and family. After you develop a plan, your CFC service coordinator will help you find providers and schedule the services identified in the IFSP to support you and your child.

The CFC offices are funded through the Early Intervention Bureau in the Illinois Department of Human Services. More information can be found at <http://www.dhs.state.il.us/ei>.

Eight principles guide the Illinois EI Program. They are listed at the end of this guide (Appendix B). The principles are emphasized throughout this guide.



I kept wondering if my baby was developing okay. Carson was 8 months old and still hadn't tried to roll over. He had trouble sleeping and was fussy all the time. He seemed more difficult than other babies I knew. So I talked to our pediatrician and he referred us to the Child and Family Connections Office. They were great! They understood my concerns and listened to me. They watched me play with Carson and recommended that Carson have an evaluation by a team of specialists. I was at the evaluation and provided information and his medical records.

Afterwards, we met and they told me that Carson was showing developmental delays in motor and social-emotional development. We wrote a plan for services and my service coordinator helped me to choose a physical therapist (PT) and developmental therapist (DT). I was relieved to know I had been right to ask for help. We had PT services for almost a year and they made a big difference in helping Carson to explore more, to roll, then crawl, and eventually walk and run. I also learned how to encourage and support his efforts and to let him try more. The developmental therapist worked with us until Carson turned 3 years old. She helped me establish routines and showed me different ways to play and connect with my son. I felt like I was part of a team. It made all the difference in the world for our family.



What are early intervention (EI) services?

Early Intervention services are designed to meet an infant's or toddler's needs in these areas of development:

- Physical (how your baby moves and explores)
- **Cognitive** (how your baby learns)
- Communication (how your baby lets you know what he needs)
- Social-emotional (how your baby engages with you and shows feelings)
- Adaptive (how your baby uses new skills)

If your child has delays in one or more of these areas, your child may benefit from EI services.

Your child's needs determine the number of services your family receives. Most families receive between one and three services. The number can vary based on

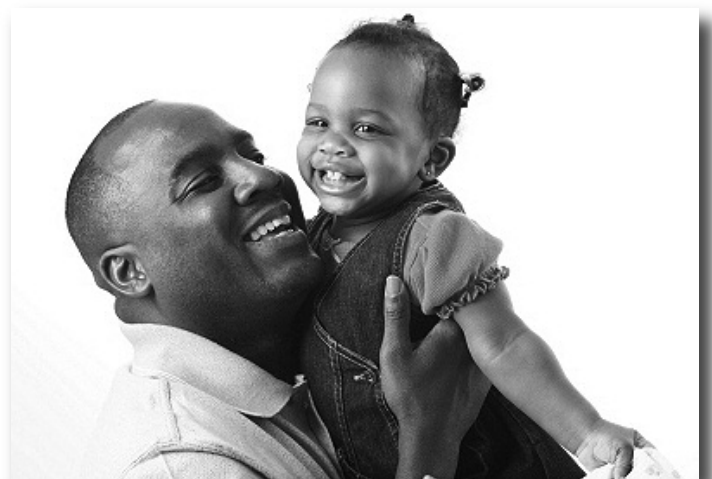
your child and family's needs and priorities. As these change over time, the number of services can also change. Currently, EI services may be conducted in one or more of the following areas:

- Assistive technology/aural rehabilitation
- Audiology
- Developmental therapy/special instruction
- Family training and support
- Health consultation
- Medical services (only for diagnostic or evaluation purposes)
- Nursing
- Nutrition
- Occupational therapy
- Physical therapy
- Psychological/counseling services
- Service coordination
- Social work
- Speech language
- Transportation
- Vision

Who is on your **service provider** team is determined by your child and family needs.

Why are early intervention services important?

The first three years of your child's life are very important. Your child's brain and body are growing rapidly. In fact, your baby will more than double in size every year. At the same time, your baby is learning about the world around him. He is learning to move, to communicate, and to expect routines. He is also learning to recognize his family, familiar places, and things around him. He needs your love and support to grow and learn.



We know that every child is unique and special. If your child was born early or was very small, she may need support to develop like other babies her age. If your baby's birth was normal and healthy, she most likely will continue to grow and thrive. But sometimes, delays are noticed only when babies become toddlers and miss important milestones. The reasons for your child's delay may not be obvious or ever identified.

A list of common developmental milestones can be found in Appendix C. You may want to check your child's development against these milestones. But keep in mind that children usually meet milestones over a several-month period. One child may develop differently from another.

If your baby was born with a disability, he may need extra help to learn and develop new skills. EI can provide that help so that your child can reach his potential during this remarkable time of life. If your child is developing more slowly or differently, then EI can support you and your child in continuing to learn and grow. It can also help others understand your child's special strengths and gifts.

If you are concerned about your child, you can ask for an evaluation at any time during the first three years. An early evaluation is important. It can help you avoid worrying when your baby doesn't reach milestones at the same time as his brothers or sisters or playmates. If the evaluation shows that your child has a disability or a delay of 30%, then you and your child may be eligible for services. You will receive help from specialists who will work with you to support your baby's development.

II. Is your child eligible for the Early Intervention Program?

Here are the steps for finding out if your child is eligible.

Step 1: Contacting your local CFC office

You may call your local Child and Family Connections (CFC) office to talk with a service coordinator about your concerns. Your doctor or child care provider may also refer you to the local office. Once you contact the CFC, they will assign a service coordinator to meet with your family. He or she will talk with you about

your concerns about your child's development. If you choose to have an evaluation, the coordinator will refer your family to a team of professionals to conduct the evaluation. The evaluation is free to families. Contacting your CFC is often described as a **referral** for evaluation.

Step 2: Meeting with a service coordinator for an intake visit

During the **intake visit**, you will be asked to sign a consent form for your child's evaluation. The referral and the evaluation are free. The purpose of the evaluation is to determine if your child is eligible for EI services. The evaluation will also help determine which services will help your child.

To begin the evaluation process, the service coordinator will need information about your child's growth and development and medical history. She may ask you to have copies of your child's medical records. She may also ask you to answer questions or fill out forms about his growth and development. You may request help in completing the forms. *(If English is not your primary language, an interpreter will be found to help you in completing the forms.)* The evaluation team will need this information about your child's strengths and needs. The service coordinator and evaluation team will ask you about your concerns, priorities, and resources.

Your EI service coordinator...

- is the first point of contact in the EI System (receives referral),
- coordinates evaluations to determine eligibility for services,
- helps families understand their roles and legal rights in the EI System,
- assists the family and other EI team members in developing and implementing the IFSP,
- contacts the family monthly while child is in EI,
- develops and maintains the case (service) record for the child and family, and
- assists the family in leaving EI services when the child turns 3 years of age.

Step 3: Participating in the multidisciplinary evaluation

The Illinois EI Program promotes a team approach. Families and professionals are equal partners on the evaluation team. You know your child better than anyone else. Your CFC service coordinator is also on the team. At least two professionals will be a part of the team. Most of these professionals will have a credential in early intervention, in addition to a license in their specialty area (e.g., speech therapy).

When professionals from several areas work together, the evaluation is called a *multidisciplinary evaluation*. The numbers and types of specialists will depend upon the concerns you've expressed about your child and the needs of your child. The team will evaluate your child in each of the developmental **domains**. These include communication, cognition, social-emotional development, physical development, and self-help skills.

The team will use age-appropriate tests and assessments to determine your child's **developmental age**. They will observe your child and ask him to try certain tasks. The evaluation will take place using your native language or the method of communication used by your family. They will respect your family's culture and ethnicity during the evaluation.

Assessments are informal and formal. The EI team relies on your observations of your child during family routines, such as play time, bath time, and dinner time. As a member of the team, you may be asked to describe what you see at home or child care. Or you may use a checklist to identify your concerns and your child's current strengths. Your team will also use assessment tools to measure your child's abilities. During the assessment, the team may ask you if your child is responding in ways that you expect or if your child is acting differently. They understand that you know what your child likes and dislikes. They will want you to participate and help them to understand your child's behavior.

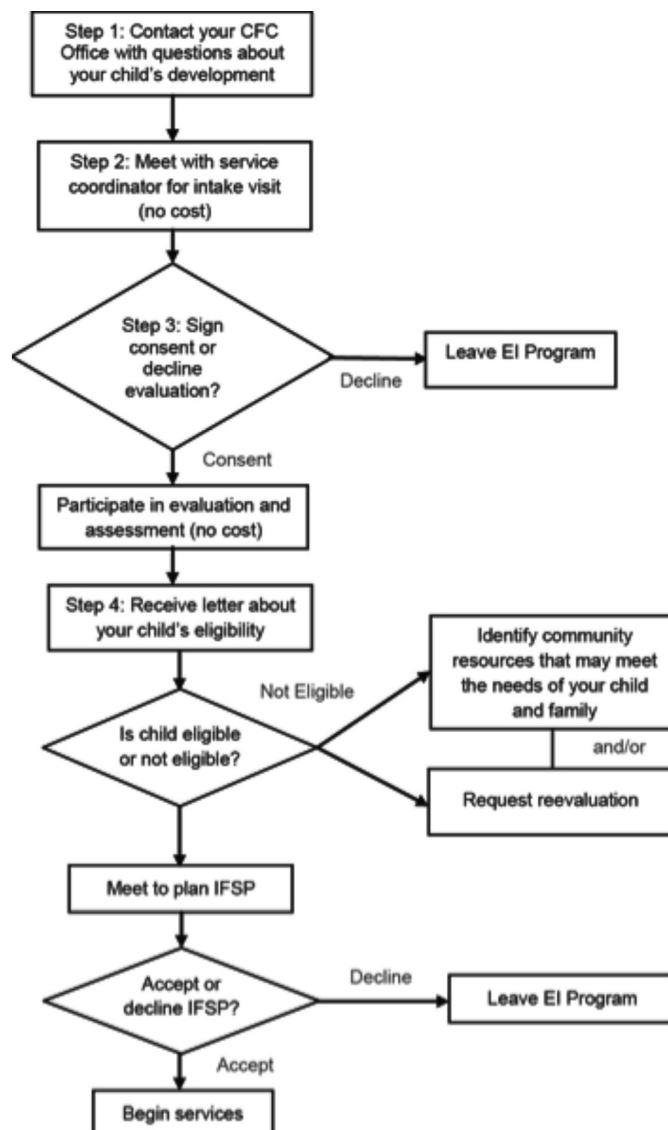
Step 4: Finding out if your child is eligible

The evaluation team and your service coordinator determine if your child is eligible for EI services. You will receive a letter stating whether your child is eligible for EI services.

Your child may be eligible if your child's evaluation shows that he or she has a developmental delay of 30% or higher in one or more areas or if your child has a disability that could result in a delay. As the parent or guardian, you can decide if you want to enroll your child in the Early Intervention Program. The program is voluntary, and you may accept or decline any EI service. You have a right to receive a copy of the evaluation team's report. For eligible children, a plan for services must be in place within 45 days.

The letter may say that your child is not eligible. If your concerns or new concerns arise, you may contact the CFC Office again and ask that your child be reevaluated.

Determining Eligibility for EI Services





The early intervention process was entirely new and a little intimidating to us. Our initial service coordinator at the CFC was great. She took time to explain all the steps in the process, she always stressed that any decisions were completely open to us, and she made sure that we were aware of all the options available to us. I felt she truly cared about our son.



III. Starting Early Intervention Services

Eligible families who choose to be in the Early Intervention Program are involved in decisions. You are part of your child's team. You will help in planning the services that you and other team members think will best meet the needs of your child and family. The first step is planning the Individualized Family Service Plan (IFSP). When the plan is finished, you, as parent or guardian, will sign the plan. Then services will begin. The plan you helped develop will describe what services are to be delivered, how often, and by whom. Many families have service providers come to their home so that family members can be an active part of the home visit. You and your team will review your child's plan and progress at least every 6 months. The following pages describe the service delivery process for you and your baby, infant, or toddler.

Step 1: Developing the Individualized Family Service Plan (IFSP)

If the evaluation shows that your child is eligible, then you—as the parent or guardian—can decide if you want services for your child in the Early Intervention (EI) Program. The service coordinator will talk with you about

- your concerns and priorities for meeting your child's needs,
- developing an IFSP to identify **functional outcomes** for your family,
- identifying services needed to meet the functional outcomes, and
- how these services are paid for.

The evaluation team and the service coordinator will meet with you to discuss the evaluation and, with your consent, to develop an IFSP.

What is an IFSP?

The IFSP is your family's written plan for EI services. It is based on your child's evaluation and the concerns, **priorities**, and **resources** you identify. It tells how your EI team will work together to address the needs that you identify as priorities for your child and family. The IFSP identifies the functional outcomes you would like for your child and your family. It identifies the services that you and your child will receive to help you in reaching those outcomes.

The IFSP is a family-centered plan. This means that families are an important part of the EI team. That's because warm family relationships set the stage for children's later growth. Your service providers are there to support you in ways that really work, or function, for you and your child.

Functional outcomes describe the ways that EI services can benefit your family and child. You and the EI team choose outcomes that relate to your family's main concerns and priorities for your child.

Outcome statements describe changes and benefits that you and your family want to see for your child or yourselves. You might begin to identify **family-centered outcomes** by asking two questions: "What benefits do I want my child to receive from EI?" and "What will be different or better for my child and family when these changes occur?"

An example of a functional outcome is "*We want Sasha to use gestures, signs, or words during her daily routines to communicate her needs and reduce the number of tantrums.*" This outcome focuses on using appropriate communication behaviors to meet needs.

Your team can measure progress toward meeting outcomes to see if changes and benefits have occurred. For example, "Is Sasha using the signs she has learned during daily routines? Does she sign for 'more milk'? Do family members respond to her signs or gestures by providing help? Have Sasha's tantrums decreased?"

Your family can also identify outcomes that consider both your child's and family's needs. These might include identifying resources that support your ability to care for your child. For example, "*The Johnson family will find a program in their community that supports parent and child interaction, such as a play group in the*

park district or story time at the library.” You and your service provider will identify the steps to reach these outcomes. Keep in mind that your priorities and outcomes may change over time as your child grows and learns.

The IFSP will also identify the roles and responsibilities of everyone involved. This means that the plan will identify *when, where, and how often services will be delivered*. Some services will come from EI specialists or service providers. But you may also wish to list supports that are informal and come from you, your extended family, and friends. Your team will work with you to make sure that you understand the IFSP and that the IFSP is written clearly and accurately.

Your service coordinator will work with you to ensure that a doctor’s prescription for direct services (e.g., physical therapy) are obtained as needed. Your coordinator will also help you determine if your family’s annual fee may be waived. No fees are charged to families whose income is at or below 185% of the **Federal Poverty Level (FPL)**.

Who should be involved in developing the IFSP?

Your service coordinator will explain the IFSP process to you. He will also set up the meeting to plan the IFSP. The coordinator should work with you to identify a date and location that is convenient for you. He will send a written notice to you confirming the meeting. You may invite family and friends to the meeting who want to support you in caring for your child. *If your child attends an early care and education program, you may invite your child’s caregivers.* In addition, the service coordinator and members of the evaluation team will work with you in developing the IFSP. The meeting, if at all possible, should be conducted in your native language.



You know your child better than anyone else. Part of your role is to let the team know what you want for your child. Your child’s plan will be based on the priorities and outcomes that are most important to you and your family. The team will recognize, respect, and encourage your family’s strengths and your dreams and hopes for your child.

How can you prepare for the IFSP meeting?

Your family is the primary source of love and support for your child. EI services are collaborative. They emphasize the family’s central role. Your family will be involved in adding new techniques into daily routines and activities with your child. So it is important for you to consider how you can assist your child in reaching functional outcomes. The worksheets at the end of this guide list questions and issues that your family may wish to consider prior to the IFSP meeting. Your service coordinator may also provide you with materials to read before the meeting.

The plan will have functional outcomes that help your child to

- gain and use new knowledge and skills,
- improve social and emotional skills, and
- use appropriate behaviors to meet his or her needs.

What does your signature on the IFSP mean?

At the completion of the IFSP process, you will be asked to sign the document to indicate your agreement with the plan. You will receive a copy of the IFSP.

If you disagree with some or all of the plan, you have the right to

- ask for changes and to share your concerns,
- accept or refuse any of the services listed on the plan, and
- stop services at any time.

What happens after you sign the IFSP?

The service coordinator will offer you a choice of service providers who are available to provide EI services outlined in the IFSP. Choices of providers may be limited because of availability, insurance requirements, or the needs of your child. Typically, EI services are provided in the child’s natural environments. This means the places where your child is most likely to spend much of his time. Natural

environments can be your home, child care location, library, or other places where your family typically spends time. Natural environments allow you and your service provider to use your daily routines to teach new skills or behaviors to your child. If these activities can fit into your routines, you are more likely to do them often with your child, even when your service provider is not with you. The key principles related to natural environments are provided in Appendix D.

Step 2: Participating in services

Who provides EI services?

The Illinois EI Program requires that all service providers be enrolled. Providers who visit your home will hold an **early intervention credential**. This credential means that the provider has met the state's training and educational requirements for working with young children between birth and age 3 and their families. Providers know the rules and regulations of the Illinois EI Program.

What should you expect?

You and your EI service provider should agree on a time and day to meet. At the meeting, your provider is likely to discuss your child's current development and your questions and concerns. He or she will also suggest ways that you can work with your child to achieve IFSP outcomes. Your provider will consider you or your child's primary caregiver as a partner in EI. Because of your partnership role, your provider may show you ways to work and play with your child. She may show and explain specific techniques. The box to the right lists a number of practices that many EI providers use. You should feel free to identify practices that you prefer.

Families and providers often talk about these things:

- Your priorities for your child's learning. You know which activities or routines are most important for your child.
- Places where you spend time with your child. Talk about other places you would like to go—the grocery store, park, or library. How do you want to spend your time there? Your provider may go with you to these places. She can help you come up with

ideas that will help your child take part successfully in those settings.

- Information and advice about new ways to support your child's development. It is likely that your service provider will encourage you to access resources in your community that will be helpful to you and your child.

What Takes Place during a Typical EI Session?

A typical visit for EI services usually includes most of the following actions:

- **Advance planning for the visit.** The provider reviews notes and plans activities and strategies for the visit. The family also reviews notes from the last meeting.
- **Arriving and greeting.** The provider arrives and chats with the family; they identify goals for the session and get ready to start.
- **Engaging in activities that focus on functional outcomes.** The provider and family members work together with the young child.
- **Observing each other.** The family may observe the provider interact with their child, and the provider may also observe the family and child interact and provide supportive feedback.
- **Demonstrating and practicing new activities or strategies.** The provider may show the family new or different ways to help their child learn.
- **Sharing information and knowledge.** Both the family and provider may have information to share about development, services, supports, and the child's progress.
- **Planning activities and strategies between visits.** The provider can help the family think about ways to fit the activities they have practiced into their natural daily routines. They may also identify information that the provider or family might gather for the next EI visit.
- **Scheduling the next visit.** To ensure that services continue without interruption, the family and provider schedule the time and day of the next EI session and visit.

The worksheet at the end of this guide may help you share information about your child and family.



Our provider helped us along the way in early intervention. We wouldn't have known how to start without her guidance."

"Our therapist has been wonderful with my son; she looks out for him, and I feel like we've made progress with her help. She is a very caring person.



How can you help?

Working with the EI service provider is important. Your provider gathers information by talking with you and other family members or caregivers. Your provider also learns by interacting and observing your child in everyday routines. You can be a full partner by doing some of the following:

- Get to know your EI service providers.
- Actively take part in your child's home visits and appointments. Active involvement helps you learn strategies and skills that will help your child develop.
- Ask your EI providers to explain the activities that they are doing with you and your child. Ask for the reasons behind the activities. Knowing these things will help you work with your child between visits.
- Share information about routines and family traditions and culture.
- Talk about the places that you and your child go. Include playgroups and friends where your child spends time.
- Describe the people with whom you and your child frequently interact.
- Notice what your child is interested in. Share your thoughts about your child's strengths and abilities, likes and dislikes.
- Tell your EI provider about any concerns you have about your child. For example, do you worry that he isn't crawling or that he is having trouble eating or sleeping?
- Learn activities to promote your child's development. Include these in your daily routines. Provide lots of opportunities for your child to play

and practice new skills during everyday routines—dressing, mealtimes, diaper change.

- Identify your family's formal and informal supports and resources. Who can you contact for help? What do you have that you can use to help your child?
- Ask for help when needed. Let family, friends and providers know how they can help during challenging times.
- with and talk to your child. Let your child know that he or she is special and loved.

How can you find parent support?

Each CFC has parent liaisons who are parents of children with disabilities or delays and who have been through the EI System. Their role is to provide information and support to interested families. They can help connect you with other families and provide you with information about your child's diagnosis. They can also be your advocate and provide the personal support that you may sometimes need.

What can you do if you have concerns about the services or your provider?

You should discuss your concerns with your service coordinator. He or she contacts you monthly to discuss your services and your child's progress. You have the right to stop services, to find a different provider, and to request an IFSP meeting to discuss a change in services. See Section V for more information on your rights.

The box on the next page lists ways to address concerns about your services or service providers.

Step 3: Six-month and annual reviews

An IFSP can be changed. As your child grows and develops, he or she may need new or different services. The EI team can change services to better meet the needs of your child and family. The IFSP team reviews the child's progress at least every 6 months. If the IFSP is not revised during a 6-month review, then it will be updated at the next 6-month (one-year) review. The plan should be updated at least once a year; however, if your needs change, the plan can be reviewed and changed more often.

Ways to Address Your Concerns

- Be prepared to problem solve with the people who work with you and your child.
- Be clear about your concerns, needs, and fears. State them before making demands.
- Keep a calendar of dates/times that your providers work with you and your child.
- Document all contacts and steps you have taken to seek solutions.
- Use the “chain of command” when your concerns are unresolved. That is, start first with your service providers, then your service coordinator, before going to the manager of the CFC.
- State your request and expectations clearly. Allow time to develop solutions. Make sure you are clear on who will take the next step.
- Follow up on verbal requests in writing.
- Ask for a response or meeting within a specific time frame.
- Focus on results. Don’t let personality conflicts get in the way.
- Request a different service provider if differences between you and a professional cannot be resolved.
- Get copies of laws and policies that relate to your specific areas of concern. Seek help from knowledgeable professionals and parents to help you understand these documents.
- Understand that the Early Intervention Program provides developmental services to help your child develop and learn. Other resources should be used for medical services.

You may want to ask the following questions at every review:

- Has our child made progress?
- Do the new outcomes require different or additional services?
- Have our priorities for our child changed?
- What services might our child need in the future?
- Has our child met the functional outcomes of the IFSP? Are new outcomes appropriate?
- Has our family met the functional outcomes of the IFSP? Are new outcomes needed?

The purpose of the annual review also is to determine if your child continues to be eligible for EI services.

IV. When is it time to leave the Early Intervention Program?

If your child began EI services as a baby, you may go through several IFSP reviews. By the time your child is 30 months old, you and your EI team will begin planning for your child’s transition from the EI Program to other services. **Transition** means a change in services. The Illinois EI Program ends for families when their child turns 3. To ensure that your child and family continue to receive appropriate services and supports, your service coordinator will work with you to look at options for your soon-to-be 3-year-old. If you feel that you need more time, you can begin the process earlier than 6 months before your child turns 3.

If your child is eligible for specialized services after his or her third birthday, you will develop a plan for these services. The plan is called an **Individualized Education Program (IEP)**. Your school district will be responsible for determining your child’s eligibility for continued services and for developing the plan with you. The **Illinois State Board of Education** and the Bureau of Early Intervention (IDHS) have provided a workbook to assist families, EI providers, and preschool service providers. The manual is called *When I Am 3, Where Will I Be?* It outlines the steps you will take in planning for services that follow EI. It helps you identify your dreams for your child and how you can share information about your child. It describes the transition planning conference, the eligibility evaluation for new services, and the IEP meeting to identify goals for your child and services appropriate for meeting those goals.

Your CFC service coordinator, a representative of the local school district, and a team of professionals will meet and work with you to plan your child’s next stage of services. You will have a transition planning meeting at least 90 days before your child’s third birthday.

If your child is not eligible for specialized services, your CFC coordinator will help you consider other appropriate services in your community.

V. What are your legal rights?

The Early Intervention (EI) Program in Illinois was established by Illinois law to comply with Part C of the federal **Individuals with Disabilities Education Act**. IDEA includes EI services for eligible children starting at birth until the third birthday. This act defines your rights as a parent of a child who is receiving EI services.

Some of your parental rights are described briefly here. More detailed information is available in *State of Illinois Infant/Toddler & Family Rights under IDEA for the Early Intervention System (2007)*, available at <http://eiclearinghouse.org/documents/family-rights.pdf>.

Informed Consent

Informed consent means that your EI service coordinator is required to give you the following information when you agree to start EI services. The information you will receive includes the purpose of the visit, how the service will be provided, who will provide the services, and what will happen if you do not consent. (If you do not consent, services cannot be provided.) If you understand and agree with the service plan and want to give permission for it, you provide written consent. This is considered informed consent.

Prior Written Notice

Written notice must be given to you before an agency or service provider makes a change in your child's EI services. Notice must be given in the language that you usually use. You should receive written notice of any



meetings, so that you have plenty of time to make arrangements to attend. Notify your service coordinator if the date, time, or location of the meeting is not convenient for you.

Review of Records

You have the right to review any records related to your child's EI services. Records must be available to you no later than 5 working days following your request.

Confidentiality of Records

All records of your family's EI services are confidential. Your providers will share information with each other to provide the best services for your family. The records will be shared with others only as privacy laws allow.

Resolution of Concerns

If you have concerns about services, or if you disagree with decisions about your child, you should discuss them with the CFC. These services or decisions may have to do with identification, evaluation, assessment, placement, or the appropriateness of the services. If you are not satisfied with the result of the discussion, formal options for administrative resolution are provided in the law. These include:

1. Compliance Complaints. You may file a written, signed complaint with the Illinois Department of Human Services (IDHS) if you believe that a provider has violated a law or rule regarding the Part C Early Intervention Program. The statement must contain the facts that support the complaint.

IDHS has 60 days from receiving the complaint to investigate and write a decision. During this time, IDHS may carry out an independent investigation.

IDHS must give you an opportunity to submit additional information either orally or in writing. The decision must include findings from the investigation, conclusions, and a reason for the final decision. If the complaint is found to be true or valid, then the decision must include procedures to correct the cause of the complaint.

2. Mediation. If you have a disagreement with the local

provider, the CFC, or IDHS, you can request **mediation**. Mediation must be conducted by a qualified mediator in a location convenient for you. The mediator's role is to help the disagreeing parties to talk and reach an agreement. The mediator cannot order an agreement. Discussions that are held during mediation are confidential. Mediation is voluntary, and you must freely agree to participate in it. The State pays for the cost of mediation.

3. Impartial Administrative Proceeding. An impartial administrative proceeding is similar to a court hearing. The hearing must be held at a time and place that is reasonably convenient to you. A hearing officer listens to both sides of the disagreement. The hearing officer may not be an employee of any agency or other entity that is providing EI services for your child. At the hearing, you may bring an advocate who has special knowledge or training about your child or about children with disabilities. You also have the right to bring your child and to have the hearing open to the public.

You have the right to a copy of the record of the hearing, findings, and decisions, at no cost. The written decision must be mailed to you within 45 days after your request for an impartial hearing. You have the right to appeal the decision.

VI. Questions frequently asked by families

What if I don't want a service?

The EI Program is a voluntary program. You have the right to decline services (unless withholding services would result in serious harm for your child). You may decline one service and still receive the other services identified in your IFSP.

What EI services are free?

There are no fees for contacting your Child and Family Connections (CFC) office to discuss concerns about your child. The process of evaluating your child for services is free. All service coordination also is free. You are also not charged for the development of the Individualized Family Service Plan (IFSP) or for the 6-month and annual reviews or transition planning meetings.

What is a family participation fee?

The Early Intervention Program requires that families who are able pay a participation fee. Participation fees are calculated on a sliding scale that is based on your annual income. You can pay the fee in monthly amounts.

Can fees be waived?

Families whose income is at or below 185% of the Federal Poverty Level are not asked to pay a fee for their participation. Under certain conditions, you may request that the fee be waived. If your family income or size changes, you may request an adjustment to your family fee. You must work with your service coordinator to make these requests.

If I have health insurance, is it used to pay for services?

If your family has private health insurance, you will need to share this information with your service coordinator. Your coordinator and providers will bill the insurance company for the cost of services. Costs that insurance does not cover are billed to the Illinois Early Intervention Program.

What questions might I ask my service provider?

Examples of these include information on contacting your provider for scheduling or canceling an appointment. For example, "What is the best way to contact you if I need to cancel?" Another concern may be how you can best participate as a partner in the session. For example, "What is the best way for me to be involved during the visit?" Other questions might include asking for assistance in identifying community resources. For example, "What are good resources in the community for parents like me?" "Are there community playgroups my child might be part of?"

How can I keep all the information that I get from my EI providers organized?

Some parents use a folder to keep all the reports and other documents that they receive from the CFC. They may use another folder or notebook to keep



information that they receive from their service providers. Many parents identify one place at home to keep all the notes and papers. You may want to keep a calendar handy to record all your appointments and visits.

What do all the terms used in EI mean? Where can I get more information and help?

Like many service programs, the EI Program has many different terms and labels to describe the program, the services, and the providers. The glossary in Appendix A will help you understand terms. You may also want to visit the Illinois Early Intervention Clearinghouse Web site at <http://eiclearinghouse.org/>. The Clearinghouse is designed for families who use EI services. Its site provides a variety of EI information and a link to its library catalog. You can borrow books and videos (at no charge) that will support you during your time in the EI Program.

How can I find other parents who are receiving EI services?

Your service coordinator and parent liaison may be able to help you find a parent-to-parent group or other resources in your community.

Appendix A

Glossary

Assessments/Evaluations

May be formal or informal. A formal initial assessment determines eligibility for services and is usually conducted in five developmental domains (see below) by a multidisciplinary team. Periodic formal assessments also take place while the child is in the Illinois Early Intervention Program. Ongoing informal assessments are used to identify the strengths and needs of the eligible child and the family's concerns, priorities, and resources related to the child.

Child and Family Connections (CFC) Offices

Twenty-five offices funded by the Illinois Department of Human Services that serve as regional points of entry to the Illinois Early Intervention Program. CFC offices responsibilities include Child Find activities, intake of families, coordination of evaluation and eligibility determinations for children, oversight of the development of individualized family service plans, and ongoing service coordination, including transition to services after the child turns 3 years of age.

Child Outcome

Please see *functional outcome*.

Cognitive

The area of development that involves thinking skills, including learning and problem-solving skills.

Developmental Age

Determined by measuring the age at which your child demonstrates various skills against the age at which those skills are considered typical. Developmental age is established through a formal assessment.

Developmental Delay

The condition of a child who is not gaining new skills at the typical age and/or is showing inappropriate behaviors for his or her age.

Domains

The five main areas of development that address cognitive, language, social-emotional, adaptive skills, and physical skills, including hearing and vision.

Disability

A physical or mental impairment that significantly limits major life activities such as hearing, seeing,

speaking, walking, caring for oneself, moving, learning, or working.

Early Intervention

Specialized services provided to infants and toddlers who show signs of or are at risk for *developmental delay* (see above). Services are planned and implemented with the family and often a multidisciplinary team of professionals. See also *Illinois Early Intervention Program*.

Early Intervention Credential

A credential issued according to Illinois Department of Human Services rules that helps to ensure that professionals working in the Illinois EI System possess appropriate qualifications, continuously participate in professional development related to their fields, and strengthen their understanding of children ages birth to 3 with special needs.

EI Providers

Please see *service providers*.

Family-Centered Outcomes

Please see *functional outcomes*.

Federal Poverty Level (FPL)

A measure based on family income used to determine if a person or family is eligible for assistance through various federal programs. The FPL usually changes annually.

Functional Outcomes

Statements of what family members want to see happen for their child or their family as a result of their participation in early intervention. Outcomes can focus on any area of child development or family life that a family feels is related to its ability to enhance the child's development. Functional outcomes often include a real-life context.

IDEA

Please see *Individuals with Disabilities Education Act of 1990* or *Individuals with Disabilities Education Act (Part C)*.

IDHS

Please see *Illinois Department of Human Services*.

IEP

Please see *Individualized Education Program*.

Illinois Department of Human Services

The state agency that has been designated as the lead agency for the Illinois Early Intervention Program.

Illinois Early Intervention Program

A statewide, comprehensive, coordinated, interagency program that aids families who have infants and toddlers, birth to three, with or at risk for developmental delays in receiving resources and supports that assist them in maximizing their child's development.

Illinois State Board of Education

The state agency that oversees educational services for children ages 3 to 21 in Illinois.

Individualized Education Program (IEP)

An annually reviewed document required by the Individuals with Disabilities Education Improvement Act of 2004 for children in special education, ages 3 years and older. The IEP is created by parents, teachers, service providers, and school staff who design a plan of instruction, including annual goals, methods of evaluation, and the delivery of special education support and services.

Individualized Family Service Plan (IFSP)

A written early intervention plan developed and implemented by the child's parents and a multidisciplinary early intervention team. The IFSP takes into account the family's priorities, concerns, resources, and goals for their child. This information, along with input from additional evaluation and assessment, is formalized into a plan of services and support for the child and family in their natural environment.

Individuals with Disabilities Education Act (IDEA) of 1990

A federal law amended in 1997 and reauthorized in 2004 that amends the Education for All Handicapped Children Act of 1975. IDEA ensures services to children with disabilities throughout the nation and governs how states and public agencies provide these services. Part B focuses on services to preschoolers and school-age children with developmental disabilities. (*See also Individuals with Disabilities Education Act (Part C)*).

Individuals with Disabilities Education Act (IDEA) (Part C)

The portion of the federal law that focuses on services to infants and toddlers who are at risk for or have *developmental delays* (*See also Individuals with Disabilities Education Act of 1990*).

Informed Consent

The process by which families acknowledge in writing that (1) they have been fully informed of all information related to an early intervention activity, (2) they agree to carry out the activity for which consent is sought, and (3) they understand that the granting of consent is voluntary.

Intake Visit

Following a *referral*, the process of service coordinators contacting the family and scheduling an appointment to discuss the Early Intervention Program, including services and fees, family rights, and initial screening. The intake appointment gives families an opportunity to ask their service coordinator questions and share information about their child and family.

Least Restrictive Environment (LRE)

The educational setting that allows a child with disabilities to gain the most educational benefit while still participating in a regular educational environment to the greatest extent appropriate. LRE is a requirement of the Individuals with Disabilities Education Improvement Act of 2004 and usually applies to children 3 years of age and older.

Mediation

One option within the Illinois Early Intervention Program that parents can request when they have an individual child complaint regarding services and want to reach a consensus with another party. Mediation is voluntary and agreed to by the parties in dispute and is conducted by a qualified impartial mediator.

Natural Environments

Home and community settings in which children and families without disabilities would participate. The Individuals with Disabilities Education Improvement Act of 2004 Part C mandates that infants and toddlers with special needs be served in natural environments.

Priorities

Important components of a child's early intervention services identified by families and given specific attention by the early intervention team. Priorities are established by order of importance in a child's *Individualized Family Service Plan (IFSP)* (see above).

Referral

Any action that guides children and families to the local Child and Family Connections Office, which assists them in accessing available resources and/or information. Anyone who suspects that a young child has a developmental delay or is at risk for delay can make a referral by calling his or her local Child and Family Connections Office.

Resources

Persons, agencies, materials, or other supports available to families that can be used to support their ability to care for their child or benefit their child's early intervention services.

Service Coordination

The activities carried out by the service coordinator to enable an eligible child and the child's family to receive authorized services within the Illinois Early Intervention Program. These activities may include receiving referrals, ensuring procedural safeguards, protecting rights, documenting services, providing information about services and assisting in identifying goals.

Service Coordinator

A Child and Family Connections employee responsible for *service coordination* activities, including coordinating EI and non-EI services for families enrolled in the Illinois Early Intervention Program.

Service Provider

A professional contracted by the Illinois Early Intervention Program to provide services for children with or at risk for a *developmental delay*. Service providers are credentialed by Illinois Department of Human Services. They can include but are not limited to occupational therapists, developmental therapists, physical therapists, and speech-language pathologists.

Transition

The organized process of helping children who have or are at risk for a developmental delay move between programs, including the Early Intervention Program.

Examples of transitions include moving from the hospital to home or from Early Intervention Program services into a preschool program. The child's family and interdisciplinary team are responsible for developing a written transition plan that details the necessary steps for a smooth transition out of the Early Intervention Program.

Appendix B

Principles of Early Intervention

1. Children in need of early intervention (EI) services are identified and can access services.
2. The primary goal of EI is to support families in promoting their child's optimal development and to facilitate the child's participation in family and community activities.
3. The focus of EI is to encourage the active participation of families in the therapeutic process by imbedding intervention strategies into family routines. It is the parents who provide the real early intervention by creatively adapting their child care methods to facilitate the development of their child, while balancing the needs of the rest of their family.
4. EI requires a collaborative relationship between families and providers, with equal participation by all those involved in the process. An ongoing parent-professional dialogue is needed to develop, implement, monitor, and modify therapeutic activities.
5. Intervention must be linked to specific goals that are family centered, functional, and measurable. Intervention strategies should focus on facilitating social interaction, exploration, and autonomy.
6. Intervention shall be integrated into a comprehensive plan that encourages transdisciplinary activities and avoids unnecessary duplication of services. The plan shall be built around family routines, with written home activity programs to encourage family participation in therapeutic activities on a daily basis.
7. Intervention should be monitored periodically to assure that the strategies implemented are successful in achieving outcomes.
8. Children and their families in the Early Intervention System deserve to have services of highest quality possible. High standards will be set for the training and credentialing of administrative and intervention staff. Training, supervision, and technology will be focused to achieve excellence.

Source: Illinois Department of Human Services
(<http://www.dhs.state.il.us/page.aspx?item=31214>)

Appendix C

Developmental Milestones from Birth to Age 3

The milestones listed below are typical for young children. **Please remember that every child is unique—growing and developing at different rates.** Most of the time differences between children of the same age are nothing to worry about. But for one child in 10, the difference can be related to a developmental delay.

If you have questions or concerns about a child's growth and development, call the Illinois EI Program at 1-800-323-4769 (voice/TTY).

At age 1 month, most children can...

- Raise their heads slightly when lying on their stomachs
- Briefly watch objects
- Make "noise in throat" sounds
- Pull away from a cloth or blanket on their faces

At age 3 months, most children can...

- Lift their heads and chests when lying on their stomachs
- Show vigorous body movement
- Follow a moving person with their eyes
- Recognize a bottle or breast
- Smile when someone speaks to them

At age 6 months, most children can...

- Sit with minimal support
- Roll from their backs to their stomachs
- Turn to locate and identify sounds
- Transfer objects from hand to hand and from hand to mouth
- Respond to friendly speech with a smile or coo

At age 12 months, most children can...

- Pull themselves up to stand and may step with support
- Pick things up with a thumb and one finger
- Nod their heads to signal "yes"
- Give affection
- Say two or three words

At age 2, most children can...

- Hand over toys upon request
- Kick a large ball
- Turn pages in a book (two or three at a time)
- Ask for items by name
- Recognize a familiar picture and know if it is upside down
- Use two or three words together, such as "more juice"

At age 3, most children can...

- Walk up stairs while holding the railing
- Stand momentarily on one foot
- Open doors
- Unbutton large buttons
- Verbalize toilet needs
- Stack objects of different sizes

Source: Illinois Department of Human Services, Bureau of Early Intervention
(<http://www.dhs.state.il.us/page.aspx?item=46498>)

Appendix D

Principles of Natural Environments

1. Infants and toddlers learn best through everyday experiences and interactions with familiar people in familiar contexts.
2. All families, with the necessary supports and resources, can enhance their children's learning and development.
3. The primary role of a service provider in early intervention is to work with and support family members and caregivers in children's lives.
4. The early intervention process, from initial contacts through transition, must be dynamic and individualized to reflect the child's and family members' preferences, learning styles, and cultural beliefs.
5. IFSP outcomes must be functional and based on children's and families' needs and family-identified priorities.
6. The family's priorities, needs, and interests are addressed most appropriately by a primary provider who represents and receives team and community support.
7. Interventions with young children and family members must be based on explicit principles, validated practices, best available research, and relevant laws and regulations.

Source: Workgroup on Principles and Practices in Natural Environments. (November 2007).

Mission and principles for providing services in natural environments. OSEP TA Community of Practice-Part C Settings (<http://www.nectac.org/topics/families/families.asp>)

Appendix E

Worksheets

Names and Contact Information I Want to Remember

My Service Coordinator:	Phone: Email:	Best times to call: Address:
Director of the CFC Office:	Phone #: Email:	Best times to call: Address:
My EI Providers: Name:	Phone:	Email:
Name:		
Name:		
My Parent Liaison:		
Helpful Community Resources:	Phone	Address
Park District		
Library		

Planning Our IFSP

I attended our IFSP meeting on _____

Others who attended:

Names

Role on Team

Names	Role on Team

Important things I learned about my child at the IFSP meeting:

Important outcomes we identified for my family and child:

Resources to help me understand EI and my family's IFSP:

Things that will happen next:

Who I can call if I have questions:

Worksheets

Things I Want You to Know about My Child

1. These are things I want everyone to know about my child:

2. These are my concerns now:

3. This is how my child communicates with me and others:

4. These are ways my child likes to learn new things:

5. This is what my child does when he or she needs help:

6. My child's normal schedule is:

Morning	_____	_____	_____
Afternoon	_____	_____	_____
Evening	_____	_____	_____

7. Places my child likes to go:

8. These are things I would like my child to learn in the next 6-12 months:

9. These are things I would like to learn in the next 6-12 months:

10. The ways I learn best are:

Adapted from *When I Am 3: Where Will I Be?: A Family's Transition Workbook*. (2007). Illinois State Board of Education in collaboration with the Illinois Department of Human Services. Retrieved from http://www.isbe.state.il.us/earlychi/pdf/transition_workbook.pdf.



Programs, activities and employment opportunities in the Illinois Department of Human Services are open and accessible to any individual or group without regard to age, sex, race, sexual orientation, disability, ethnic origin or religion. The department is an equal opportunity employer and practices affirmative action and reasonable accommodation programs.

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