Transition at age three:
A handbook for parents of young children with disabilities

An Honors Thesis (HONRS 499)

by

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Purpose of Thesis

The purpose of this handbook is to provide a simple, yet factual explanation of the change in service providers that occurs in many states when children with disabilities reach age three. It explains the legal reasons for this transition and describes the kinds of changes families can expect to experience. It also includes a list of parents' rights and conflict resolution strategies, as well as a listing of other available resources.

This handbook uses simple text and graphics in an attempt to make this information more accessible to families. Readers seeking more extensive and comprehensive information are encouraged to consult other sources.

ACKNOWLEDGEMENTS

I wish to thank the many parents and professionals who shared their knowledge and insights in order to guide the development of this handbook. Included in this list are Judy Lambert, Teri Truex, Charlene Hickenbaugh, Judy Lahlum, Jane Ann Moore, and Dr. Evelyn Lynch. I am especially grateful to Dr. Linda Duncan-Malone for taking the time to supervise and review the compilation of this information. A final thank you is reserved for Aaron, my best friend and support throughout this project.
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INTRODUCTION:
What is this book about?

On your special child's third birthday, he or she will no longer be able to receive early intervention services from the agency that is providing them now. This handbook was written to help you understand why this will happen and what you can expect to change.

However, please keep in mind that each family's situation is different. If you have questions about your child that are still unanswered, ask your current case manager or contact any of the resources listed in the back of this handbook.
Why will there be changes when my child turns three years old?

A law passed in 1975 (P.L. 94-142) said that schools had to provide special education services for kids with disabilities between the ages of 5 and 21. It promised to provide extra money to schools that chose to serve children aged 3-5 as well. However, serving preschoolers still remained an option.

In 1986, that law was updated, and it was given a new number (P.L. 99-457). It now required schools to serve children with disabilities from age 3-5. It also promised extra money to states if they chose to serve kids with disabilities from birth through age 2. However, the law did not require that the schools provide the early intervention. Each state had to choose a lead agency to do this, and many states chose someone other than the public schools.

Indiana chose First Steps, a part of Family and Social Services, as its lead agency. First Steps serves infants and toddlers with disabilities from birth through age two. Public schools must take over this responsibility as children turn three years old.
In every state, children with disabilities age 3-21 receive services from the public schools. The agency that provides services before age three can be different from state to state. In Indiana, First Steps serves infants and toddlers.
How will my family be prepared for change?

The law requires your service provider to do the following things to help you during the transition process:

* When your child is 18 months old, they will send his or her name, date of birth, and suspected disability to the preschool agency that is most likely to provide services next. This will tell the new service provider to expect your child.

* Six months before your child's third birthday, they will send a copy of the most recent IFSP (Individualized Family Service Plan) and testing information to the next service provider. They must get your written permission before they can do this! This will allow the new agency to plan for more testing if it is needed.

* With your permission, a meeting can be held 90 days before your child's third birthday so you can discuss plans for change with both the current and future service providers.
TIMELINE:
When things will happen

6 months before third birthday
IFSP & assessment information are sent to the next service provider with your permission

90 days before third birthday
a planning meeting is held for you and the service providers

AGE 18 months
your child's name, date of birth, & suspected disability are sent to the next service provider

your child is born

your child's third birthday
What can I expect to change?

As your child approaches the age of three:

* Expect your child to need more testing.
* Plan to give information about what you think your child's needs are.
* Be aware of different eligibility requirements for programs that serve children over age three.

If your child is found to be eligible for special education, you can also expect to experience these changes:

* You will work with new personnel. (teachers, therapists, assistants, etc.)
* There may be new locations for services and integration with other children.
* There will be a new way of making decisions.
* There will be new paperwork.
* People will use new words.
* People may have different ideas about how to serve you and your child.

The following pages explain these possible changes more thoroughly. Remember you will not necessarily experience all of them.
In order to decide if your child qualifies to receive services past the age of three, he or she is likely to need more assessment. The tests may include:

* developmental tests,
* standardized tests,
* medical tests,
* informal questionnaires,
* family interviews, and/or
* observations.

Before any testing begins, you must give written permission for it to occur. You have the right to know what tests are planned, when and where they will be given, and what information will be gathered.

Please remember: the purpose of these tests is to learn more about your child's needs and strengths. They are also required by law for your child to be eligible for special education services.
ELIGIBILITY FOR CONTINUED SERVICES

Most infant and toddler programs serve children who fit into the broad categories of being "at-risk" or "developmentally delayed." However, other programs have different requirements for entry.

* Just because your child was able to receive early intervention services does not mean that he or she will continue to qualify for services past the age of three.

Several different things could happen:
* Your early intervention team may decide that your child no longer needs any special services. Your family met all of its goals and there is no more to be done.
* Your child may meet the eligibility requirements for special education, so they can begin receiving services from the public schools.
* Perhaps your family is still in need of services, but your child does not qualify to receive special education. In this case, your early intervention team will discuss other services that might be right for your child. Options include: Head Start, day care, public or private preschool, and monitoring.
SPECIAL EDUCATION ELIGIBILITY

In order to be eligible for special education services, children have to meet certain requirements of the law. They do not necessarily qualify just because they were able to receive services as infants and toddlers.

Public schools receive funding to provide special education based on the number of children they serve with certain types of disabilities. In order to qualify for special education, a child must be given a categorical label. In other words, he or she must be tested and found to fit into one of these groups:

- Autism
- Communication Disorder
- Dual Sensory Impairment
- Early Childhood
- Emotional Handicap
- Hearing Impairment
- Learning Disability
- Mental Handicap
- Multiple Handicap
- Orthopedic Impairment
- Other Health Impairment
- Traumatic Brain Injury
- Visual Impairment

"Labeling" children is not meant to hurt them. It only makes sure they get the help that they need.
New Personnel

Most likely, your family will begin to work with new teachers, therapists, and assistants when your child turns three years old. Working with new people and leaving those you already know might be very hard for you to do. To make the changes easier, consider the following options:

* Whenever possible, meet with the new teachers and staff and get to know them before your child is put in their care. Plan an observation or have your current personnel introduce you if this makes you more comfortable.

* Feel free to ask questions and be honest about your concerns. Find out what you can do to help. They will probably appreciate your willingness to be involved.

* Maintain some contact with your former intervention team until you adjust to the changes. Be careful not to rely on them too much though! It is important for you to be able to work well with many different people to benefit your child.

* Remember that everyone involved wants to help your child. When you work together, your child is most likely to succeed! Do what's best for your child.
New Locations for Services & Integration with other children

It is most likely that your child is now receiving early intervention services at home. Often this is the most natural place for your family to be.

However, as your child grows older, it becomes important for him or her to develop social skills by playing with other children who are the same age. Being around children who are not disabled is especially helpful because they can learn how other kids do things.

Special education law requires that your child receive services in the "least restrictive environment (LRE)." The LRE is one that meets the child's needs and does not limit them unnecessarily. You will be part of the team that first plans what kinds of services your child will need, and then decides the best place for your child to receive these services.

Remember:
Special education is a service, not a place!
Case Conference Committee:  
A New Way of Making Decisions

Who are these people?

The Case Conference Committee (CCC) will be in charge of making decisions about your child while he or she is in special education. The committee is made up of the different people who are interested in your child. YOU are one of the most important members of this team! Other team members might include school administrators, teachers, related service personnel, and others you want to be involved.

Do I have to be a team member?

You do not have to participate, but you know important things about your child that no one else does. Your involvement will really benefit your child!

What kind of decisions does the CCC make?

The Case Conference Committee will:
* decide if your child has a disability that makes them eligible for special education services,
* decide what kinds of services your child needs,
* decide the best place for your child to receive those services.
When does the CCC meet?

The CCC has to meet within 40 school days of when you first give permission for your child to be tested for eligibility. It must also meet at least once a year after that, or whenever a member wants to change what services your child gets or where they will be provided. The meeting must be held at a time that is convenient for everyone who has to attend.

How can I prepare for a CCC meeting?

You should always receive written notice of the date, time, place, and purpose of the meeting. You have a right to know who is going to be there, and what will be discussed. You can also get ready by doing these things:

* Think through the needs of your child.
* Think of what he/she can and cannot do.
* Be ready to work with school staff.
* Be prepared to share as much information as possible.
* Be prepared to share what your hopes are for your child.
* Be willing to listen to the ideas of others.
* Make a list of questions and concerns.
* Confirm arrangements with the school.
* Remember that you are an equal member of the team who can contribute very much!
Another difference is that the IEP is an "education" program, not a "service" plan. It focuses only on services for your child that will affect his or her ability to learn. Related services (such as physical therapy, occupational therapy, speech, and nursing care) are still available, but the case conference committee must determine that they directly impact the child's success in school. Academic goals may become more important, and people might begin to view your son or daughter as a "student," not just a child.

Your "child" may now be seen as a "student"

Your child's IEP must be updated at least once every year. Sometimes this is called the "annual case review" (ACR). Each year you will be a part of the team that makes necessary changes in this document.
New Words and Abbreviations

As you begin to work with people from the schools, you may notice that they use different words to describe your child and/or the services they receive. Sometimes they just say groups of letters which can get confusing. Whenever someone says something that you don't understand, please tell them. You have the right to have things explained in a way that makes sense to you!

This is a list of common abbreviations used in special education that you may want to become familiar with. They are organized by category.

School Services

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ECSE</td>
<td>Early Childhood Special Education</td>
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<tr>
<td>GENED</td>
<td>General Education</td>
</tr>
<tr>
<td>OT</td>
<td>Occupational Therapy or Occupational Therapist</td>
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<tr>
<td>PT</td>
<td>Physical Therapy or Physical Therapist</td>
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<tr>
<td>SPCED</td>
<td>Special Education</td>
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Terms from Law

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>CCC</td>
<td>Case Conference Committee</td>
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<tr>
<td>FAPE</td>
<td>Free Appropriate Public Education</td>
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<tr>
<td>IEP</td>
<td>Individualized Education Program</td>
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<tr>
<td>IFSP</td>
<td>Individualized Family Service Plan</td>
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<tr>
<td>ITP</td>
<td>Individualized Transition Plan</td>
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<tr>
<td>LRE</td>
<td>Least Restrictive Environment</td>
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<td>PAC</td>
<td>Parent Advisory Council</td>
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Categories and Types of Disabilities

ADD  Attention Deficit Disorder
ADHD Attention Deficit Hyperactivity Disorder
AU  Autism
CD  Communication Disorder
CF  Cystic Fibrosis
CP  Cerebral Palsy
DB  Deaf Blind
DD  Developmental Disability
DH  Developmental Handicap
DSI Dual Sensory Impairment
EH  Emotional Handicap
FAS Fetal Alcohol Syndrome
HI  Hearing Impairment
LD  Learning Disability
MD  Muscular Dystrophy
MIMH Mild Mental Handicap
MH  Mental Handicap
Mh  Multiple Handicaps
MOMH Moderate Mental Handicap
MR  Mental Retardation
OHI Other Health Impairment
OI  Orthopedic Impairment
TBI  Traumatic Brain Injury
VI  Visual Impairment

Laws Relating to Special Education

ADA Americans with Disabilities Act
IDEA Individuals with Disabilities Education Act
P.L. Public Law
Differences of Opinion

As you begin to work with new people from the schools, you may find that they have different ideas about how to serve your child.

* Take advantage of the fact that there are many people with a variety of skills who are concerned about your child. Teams who work together almost always come up with better ideas than anyone could if they had to do it on their own.

* Remind yourself that you are a very important member of the team that makes decisions about your child's services. You have the right to be heard.

* Remind yourself that everyone else on the team also has the right to be listened to.

Learn to be a good listener by:

* focusing on what other person is saying,
* taking the other person's point of view,
* repeating or rewording what the other person says to make sure you understand it,
* looking in the person's eyes and leaning towards them a little bit, and
* being patient and not interrupting.
If you feel tense or think there may be a conflict during any of your team meetings:

* Ask a friend or advocate to be with you for moral support and assistance.

* Write down what you want to say so you don't get nervous and forget it.

* Take several deep breaths, get a drink, or ask for a short break to help you relax.

* Consider stopping the meeting and rescheduling it at another time when you can be more prepared and less stressed.

If you have a major conflict with the school and you don't think you can handle it by yourself:

* Let the other team members know. More people may agree with you than you think, and you may be able to deal with the problem by working together.

* Talk to professionals outside of the school (ex. your family doctor, psychologists, etc.) and ask for their support.

* Call Indiana Protection and Advocacy at 1-800-622-4845 to get some free answers to your questions. They will help you figure out what your options are.

* Always focus on what's best for your child!
YOUR PARENTAL RIGHTS
As the parent of a child with a disability who is being served by the public schools, you will have the following legal rights:

* You will receive a written copy of your rights from the school. This information will be in readable language that you can understand. Anything you don't understand must be explained to you.

* You have the right to meet with school personnel to discuss concerns or problems related to your child.

* You are a part of the team that makes decisions about your child. You can call a case conference committee meeting to discuss your child's identification, evaluation, placement, or educational program.

* If a case conference committee meeting is called by someone else, you should learn about it in writing and have enough time to prepare.

* You do not have to pay for your child to receive special education services.

* You do not have to provide transportation for your child to get to school.

* You can have your child evaluated by people outside the school, but in some cases you must pay for it yourself.

* You have the right to request mediation, a hearing, or file a complaint if problems cannot be resolved.
* You are allowed to see your child's educational records, request changes in them if they are misleading, and/or make copies of them for a small fee.

* More information about special education laws and procedures should be given to you if you want it.

**In addition to these legal rights, remember that as a parent you also have the right to:**

* **Get Another Opinion** -- You will feel better if you know for sure.

* **Feel Angry** -- Anger is natural when unexpected things happen.

* **Keep Trying** -- Many goals will be reached if you really work towards them.

* **Stop Trying** -- Reaching some goals takes too much time and energy.

* **Privacy** -- Don't let others control your personal life. Demand respect.

* **Be Unenthusiastic** -- We all have our "ups and downs." You are no different.

* **Be Annoyed With Your Child** -- Children can cause stress. Even the most loving parents have difficult times.

* **Take Time Off** -- We all need breaks.

* **Be The Expert** -- You know your child better than anyone else.

* **Set Limits** -- You decide what's best for your family.

* **Have Dignity** -- Everyone deserves respect.

* **Be A Parent** -- This is your special role.
Where can I find more information?

Indiana Resource Center for Families with Special Needs (IN*Source)
833 Northside Boulevard, Building 1-Rear South Bend, In 46617-2993
1-800-332-4433 or (219) 234-7101

Indiana Parent Information Network (IPIN)
4755 Kingsway Drive, Suite 105
Indianapolis, IN 46205
(317) 257-8683

Indiana Department of Education
Division of Special Education
Room 229, State House
Indianapolis, IN 46204-2798
(317) 232-0570

Indiana Protection and Advocacy
850 North Meridian Street, Suite 2C
Indianapolis, IN 46204
1-800-622-4845 or (317) 232-1150
Family Resource Center on Disabilities
20 East Jackson Street, Room 900
Chicago, IL 60604
1-800-953-4199

Council for Exceptional Children (CEC)
1920 Association Drive
Reston, VA 22091-1589
1-800-328-0272

National Information Center for Children and Youth with Disabilities (NICHCY)
P.O. Box 1492
Washington, D.C.  20013
1-800-695-0285

State-Federal Information Clearinghouse for Exceptional Children
1920 Association Drive
Reston, VA 22091
(703) 620-3660

Children's Defense Fund
122 "C" Street, N.W.
Suite 400
Washington, D.C.  20001
(202) 628-8787
MATERIALS USED IN THE CREATION OF THIS HANDBOOK


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