



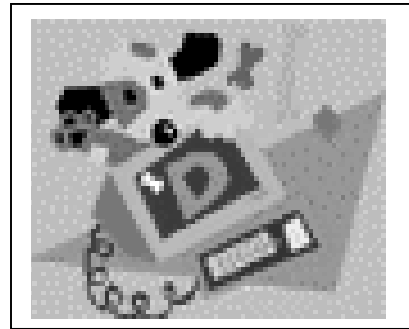
Parents' Rights

Part of the "Facts at Your Fingertips" Series of Informational Materials for Parents and Families Enrolled in the First Steps System in Vigo County

Parents' Rights. It sounds important and it is. Parents' Rights are something our service providers talk about from the very beginning of the First Steps process. We hear it dozens of times. Sometimes, however, we're so busy dealing with our children, with writing IFSP outcomes, with making sure our children are getting the supports and services that will be most helpful that we don't always take the time to really understand what Parents' Rights mean. This issue of "Facts at Your Fingertips" is dedicated to explaining the rights parents of children enrolled in First Steps have.

A Little Background Information

Why do we have Parents' Rights? It sounds like something that has to do with laws and in fact, it does. First Steps is Indiana's name for the federal program that serves infants and toddlers with disabilities and developmental delays. This federal program is part of the larger federal program known as I.D.E.A. or Individuals with Disabilities Education Act.



This law was originally passed by Congress in 1975 and later updated several times. In 1986, the law included providing services to infants and toddlers. So, it really is part of the law.

In writing the law, Congress knew that it was important to guarantee to parents of children served by the program, certain rights. By doing this, Congress ensured that parents are active participants in the process and there are protections and safeguards to ensure that the system is supportive to children and families.

The 10 points listed below will explain Parents' Rights in the First Steps system in Indiana.

1

The Right to an Evaluation

Eligibility in First Steps is based on the gathering of lots of important and relevant papers and information that help give a full and clear picture of your child's development. A 'multidisciplinary team' of professionals representing at least two different areas of expertise does the evaluation. Evaluations, or any

tests, should always be done in your child's native language. No one test can be used to determine whether or not your child is eligible. You also have the right for your child to have regular and ongoing evaluations of your child's strengths, skill levels, progress, and needs.

The evaluation should be completed within 45 days from the time your child is referred to First Steps.

2

The Right to a Coordinated Plan

Also within 45 days from the time your child is referred, your service coordinator and those people who will make up your child's multi-disciplinary team (including you) should come together to create your child's Individualized Family Service Plan (IFSP). This plan is the map for your child's services for the coming year and includes your child's and your family's strengths, priorities, needs, and the services that will help meet those identified needs, including how much service, when it will take place, where, and who will provide the service. It includes the outcomes you would like to see your child achieve. The IFSP is reviewed at least every 6 months and is rewritten every year and you are an important part of that review process.

3

The Right to Consent

The right to give consent or permission must always be obtained, in writing before an evaluation or assessment can be done and before services can be started or stopped. Parents can choose not to give consent for any particular service without jeopardizing any other services. Consent can be revoked, or stopped at any time as well.

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The Right to Prior Notice

Nobody likes major surprises and in First Steps, the rules have been created to see that you have no major surprises. Before any service can be started, stopped, or changed, parents have the right to have 10 days notice, in writing. These notices should also explain your rights and give details for the decisions that are being suggested. The notice should be in your native language and be clearly explained to you.

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The Right to Privacy

There are several things that protect your privacy. One is that, it's just the right thing to do. It is unethical for any service provider to share information about you with anyone without your permission. The other protection you have is legal. The Family Education Right to Privacy Act (FERPA) is a law that says any personal information about you cannot be shared with another person or agency or program without your permission. While it's very important that service providers be able to work with your child's other providers and this requires that they talk together, you must first give your permission for them to do so. The providers must contact you, explain the situation, and ask for your written permission. Several of the 'release of information' forms that you signed at the beginning of the program give providers the right to talk together to best plan for meeting your child's needs. Remember that their conversations are strictly professional and do not discuss your personal issues.

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The Right to Review Records

Every child enrolled in First Steps has an official Early Intervention Record (sometimes called the SPOE Chart) that is kept in the System Point of Entry (SPOE) office. Parents have the right to inspect, review, and amend their child's record. Parents also have the right to have a copy of this official record. Every SPOE filing cabinet must show a list of the people who have access to files and every individual record contains a listing of those providers who have read the files. Records are not exchanged or sent to another agency without a parent's informed, written permission. If a parent disagrees with something that is in the file, they may request that this information be changed or removed. If the provider does not agree that this information should be removed or changed, parents have the right to request an impartial hearing be scheduled to come to an agreement.

7

The Right to Participate

No one knows your child better than you do and no one is a more important member of your child's multi-disciplinary team than you are. Every parent has the right to be a full and equal partner in planning their child's services, the delivery of those services and in the evaluation of those services. Parents are such an important part of this process that meetings should never take place without their being there.

8

The Right to Understand

Every parent has the right to know exactly what is going on with their child's service plan and the types of services their child is receiving. In order for this to occur, parents need information to be shared with them in methods that are easy to understand. Information should take into account a parent's native language and any cultural issues that might be present. First Steps does not discriminate based on race, ethnic background, religion, disability,

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The Right to Have an Advocate

The First Steps process can seem overwhelming and confusing, especially in the beginning. It's important for parents to feel comfortable while they're learning the new system and comfortable as time goes on and their child participates. For this reason, parents are encouraged to build their own support system through friends, family members, and other parents who have participated in the program and other service providers. This support team can be a real help to families during any part of the First Steps process.

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The Right to Disagree

Not every part of any service delivery system will make families happy. Sometimes, parents and providers may disagree on an issue. If this happens, parents have the right to seek help in resolving any issue. As a rule, parents should first discuss any difficulty with their child's service coordinator. If this doesn't work, there are other avenues of complaint, all the way up to a complaint filed at the state level. There are parent support services available to help parents understand the complaint system.

Summary

This informational packet was designed to explain, briefly, the rights of parents who have a child who participates in the First Steps system. These rights should be shared with you, as parents, throughout the time your child is enrolled in First Steps. If you ever have a question regarding your rights, feel free to speak with your service coordinator, or call the Local Planning and Coordinating Council coordinator for more information, at (812) 231-8342.