

First Words

A First Steps Communications Tool for Families From Family to Family

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Alphabet Soup

Each month we cover a few abbreviations, terms or acronyms parents might hear or see while in First Steps. Sometimes it is awkward for families to ask. Here are just some of the abbreviations that you may see when reading reports provided by your First Steps team:

- **ADL = Activities of Daily Living**

Age-appropriate activities children do on a daily basis, including sleeping, eating, dressing, playing, and moving around their world.

- **Dx = Diagnosis**

A label assigned by a doctor or therapist to a medical or developmental condition

- **Tx = Treatment**

A recommended method for intervening in a medical or developmental condition

The Family’s Role in Transition

Transition from First Steps has been a topic on several occasions in this newsletter. Transition is a lengthy process with the end goal being that a child moves into a post-First Steps program that appropriately addresses his or her needs. The transition process requires First Steps to complete a number of required tasks throughout the process—sending notices to Lead Education Agencies at 18 and 30 months of age, scheduling a transition meeting, conducting a transition conference, etc. However, families must also take an active role in the process to ensure a smooth transition from system to system.

One key concept that families must understand is that there isn’t a “go-to” person like a First Steps service coordinator once a child transitions out of First Steps. There may be new, and possibly some ongoing, professionals (i.e. teachers, school therapists, private therapists, other medical professionals) that will work with your child, but it is unlikely that any one of these people will have the knowledge about all the services and programs your child is involved in like your First Steps service coordinator had along the way. Therefore, you as parent or guardian must be prepared to take on that role of service coordinator for your child and more than ever need to be an advocate for your child and family. By starting early to gather information about ongoing services needed for your child, you are helping to create a smooth transition for your child.

Your First Steps service coordinator will work with you on a transition plan which addresses many of the issues you will need to consider. Financial planning is a big part of that plan. What type of insurance or health program is in place to cover your child’s medical needs? Are there other programs you should apply for? What types of services will be covered? Will your child need ongoing therapies outside of school-related services? If so, are these services covered? Will you need to pick new therapists? Chances are high that you will need to travel outside the home to find therapy. Do you know how to locate potential providers? Will your child need any equipment after they leave First Steps? Do you know where to go to get this equipment? Will your insurance or health program cover these equipment expenses? All at once, these questions may seem overwhelming, especially combined with choosing an appropriate program for your child. However, by starting early to gather answers to these questions, they won’t seem so overwhelming when your child’s third birthday arrives.

So, how do you find answers to your questions? Start by talking with your First Steps providers and service coordinator. Have questions ready for your transition meeting. This is an ideal time to get answers to some of your concerns. Talk with the medical professionals your child already sees, and talk with other families to find out how they found resources and information. Find a local support group or join the Family to Family listserv to connect with other families. You may have to look to lots of different places for answers. Consider this exercise just the beginning steps on the advocacy path you’ll travel for your child.

Vision Services in First Steps

Periodically we highlight one of the lesser-utilized services in First Steps in an effort to increase the understanding of the types of services available in the system. This month we bring you the following information on vision services, as outlined in the First Steps Family Handbook.

First Steps 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. The mobility specialist will coordinate these activities with other professionals serving your child as well as your child’s primary care physician.



Advocacy Tip Of The Month

Do you make a new year’s resolution each year? If so, you might consider making a resolution around advocacy for your child and family! Here are some ideas to help your child and family in 2007.

- *Get to know your legislators. Make an appointment early in the legislative session. You don’t have to have an “agenda” to meet them. Just introduce your family and highlight two or three issues important to your family. Offer to serve as an advisor on these issues when they are under consideration this session.*
- *Strengthen relationships with members on your child’s team. If you have great relationships with everyone who serves your child, strengthen them by actively giving positive feedback to those providers. If you are struggling with someone on the team, take at least one positive step to improve the relationship. Forgive past disagreements, real or perceived. Extend the “olive branch” and start over with a clean slate.*
- *Expand your knowledge. Perhaps you’ve always wondered about a specific type of instruction that might help your child. Maybe you have heard about treatment options you want to explore. Sometimes we don’t pursue new things because the research takes hours and hours. Set aside a specific amount of time you will devote to your research and then dive in. Maybe you will learn something new that will really benefit your child, and maybe you’ll discover this isn’t a good route to pursue. Either way, you’ll feel empowered by learning something new and making an informed decision.*

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 purposes of correcting your child’s vision.

Resources for Families

Check out these resources on health care and other services available for Indiana children with and without disabilities:

[Indiana’s Division of Family Resources](http://www.in.gov/fssa/family/services.html)
<http://www.in.gov/fssa/family/services.html>

[Hoosier Healthwise](http://www.in.gov/fssa/maternal/hoosier_healthwise/)
http://www.in.gov/fssa/maternal/hoosier_healthwise/

[Indiana Comprehensive Health Insurance \(ICHIA\)](http://www.onlinehealthplan.com)
(be sure to log in as a guest to view the benefit info)
<http://www.onlinehealthplan.com>

[Indiana Children’s Special Health Care Services](http://www.in.gov/isdh/programs/cshcs/)
<http://www.in.gov/isdh/programs/cshcs/>

[Social Security Income \(SSI Disability\)](http://www.ssa.gov)
<http://www.ssa.gov>