

Year at a Glance

2011-12



*“Leah All Smiles”*





## “A Mere ‘Thank You’ Will NEVER be Enough!”

Where do I begin? First Steps has done so much for my family that it is almost impossible to even put into words the gratitude I have and the indebtedness I feel to everyone who has been involved in helping us. We began our journey with First Steps almost 3 years ago. My husband and I received custody of our two young grandchildren; Leah was a mere 6 months old, and her brother Jordan had only just turned 2. Leah was diagnosed with Failure to Thrive and Scalding Skin Syndrome. We knew at that time Leah was going to need so much help. We knew very little about the journey we were about to undertake.

When we contacted First Steps for help, the response was immediate. Cindy, our coordinator, came out to see us and connected Leah with therapies right away. The knowledge, kindness and understanding Leah's therapists and Special Instructor Zanetta, Carrie and Jan, have given me has been such a strong support system for me! They have guided me through this difficult process and given me the direction and shoulders to lean on that I have so often really needed. They have been here and stuck by me every step of the way. Together we have helped Leah grow from a baby that could not even lift her head up, to a happy child who loves to run and jump and play. They have taken so much time and patience to show me the ways to work with Leah, to help her succeed.

On June 2, 2011, Leah was diagnosed with Autism. It was a diagnosis we expected, but it was a really hard pill for me to swallow. Leah's First Steps providers helped me to understand that Autism is not what defines Leah, it is just a part of who she is! Cindy immediately started preparing me for the next journey that we were about to undertake. She kept in constant contact, checking on Leah's progress and services and connecting us with lots of resources.

I truly believe that if we had not had the services and the commitment from those involved in our lives through the First Steps program, Leah would NOT be as far along as she is today. This is a program that can change not only the course of a family's life, but also give our children the opportunity to grow, succeed, and be ALL they can be! Leah is where she is today because of First Steps. Thank you for giving my Leah a solid start in life, for giving us the strongest foundation to build on, and for bringing love and compassion to our family.

**By Jennifer of Newburg, MO**

*From the cover...  
Leah's Story*



Leah “loves to run and jump and play”.

## Who is Eligible for First Steps?

Infants and toddlers, birth to age 3, who either:

- 1) have a diagnosed physical or mental condition associated with developmental disabilities (such as Down syndrome, spina bifida or cerebral palsy),
- 2) have a condition with a high probability of resulting in a developmental delay or disability (such as a very low birth weight child who has experienced intracranial bleeding or ventilator dependency), or
- 3) are functioning at half the developmental level expected for a child of equal age in one or more of the following areas:
  - \*communication
  - \*adaptive
  - \*physical (including vision and hearing)
  - \*cognitive
  - \*social/emotional

Eligibility is determined through an initial evaluation and assessment. This includes the service coordinator collecting information about the child's birth, medical and developmental history and/or an evaluator administering a test to determine the child's current abilities. The evaluation is typically conducted in the family's home or another natural environment.

## Who Referred Families to First Steps?

First Steps accepts referrals from parents as well as many community programs such as hospitals, physicians, child care centers, preschools and other public agencies.

| Referral Sources  | % of Active Children |
|---|----------------------|
| Parents   | 44.5%                |
| Medical Providers (Hospitals, Physicians, Other health care, Public health)                                   | 38.5%                |
| Early Childhood Programs (Parents as Teachers, Early Head Start, school districts, child care programs, etc.) | 12.2%                |
| Social Service Agencies (Mental Health and Health & Senior Services)  | 3.8%                 |
| CAPTA (Child Abuse Prevention and Treatment Act)  | 1.0%                 |
| TOTAL   | 100%                 |

## When Families Made the Referral, How Did They Learn About First Steps?

| Families learned of First Steps from:   | % of Parent Referrals |
|---|-----------------------|
| Medical Providers (Hospitals, Physicians, Other health care, Public health)                                   | 44.6%                 |
| Other Sources   | 34.3%                 |
| Early Childhood Programs (Parents as Teachers, Early Head Start, school districts, child care programs, etc.) | 19.5%                 |
| Social Service Agencies (Mental Health and Health & Senior Services)  | 1.6%                  |
| TOTAL   | 100%                  |

### Caleb and Chloe: The Wonder Twins

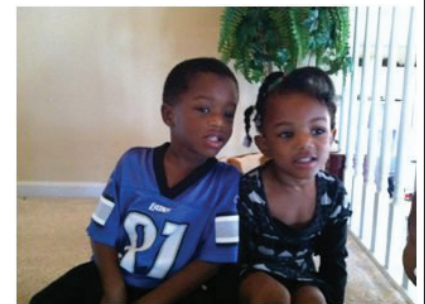


Danielle and Ashley with Caleb and Chloe

On January 8, 2009 my world was blessed with two precious gifts from God. Although Caleb and Chloe arrived a few months early, they arrived in this world with miraculous beginnings and are still amazing many people. Caleb and Chloe were born respectively at 09:51 and 09:54. They spent a couple of months in the NICU at Mercy hospital in Saint Louis, MO. They were constantly beating the odds with hearing test, vision tests and mini milestones they accomplished within the hospital. I diligently made a commitment to myself... I would do whatever it takes to make sure these babies would make it!!

When Chloe and Caleb came home from the NICU I was a nervous wreck. My husband and I had things set up at home to make sure the transition from NICU to home was easily done. The hospital staff had mentioned to us about the First Steps program for additional support and services. We were thrilled to have the help in the comfort of our own home as well as subject matter expert's to guide us through each milestone along the way. Chloe received Nutritional, Occupational and Physical Therapy services with First Steps. Caleb received only one service with the program- Occupational Therapy.

Chloe and Caleb excelled in all the services that we were recommended. They both are happy healthy 3 ½ year olds who are currently in preschool doing very well with letter recognition, finding new friends, sharing and reading. They are enthusiastic about their soccer lessons and Chloe is now loving and participating in ballet. They both are very caring and loving children with their little sister Carley (18 months). I always try to stay on top of things with them, so I had them tested in 2011 prior to their third birthday within the Wentzville School District to see if they would qualify for special services and both children surpassed all expectations and did not qualify for the early childhood center. I had them tested again for good measure and the same answer both children were noted as doing very well! My advice to parents of premature kids is to never give up and do whatever it takes to help them succeed!!! We can do more for them than we ever could imagine!!! I'm so proud of them in every way. They have many more milestones but I have no doubt these kids will accomplish it all and then some...



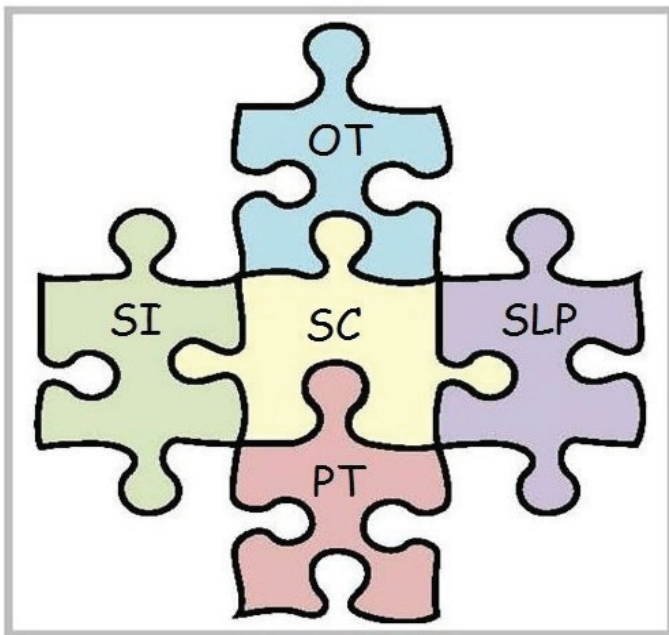
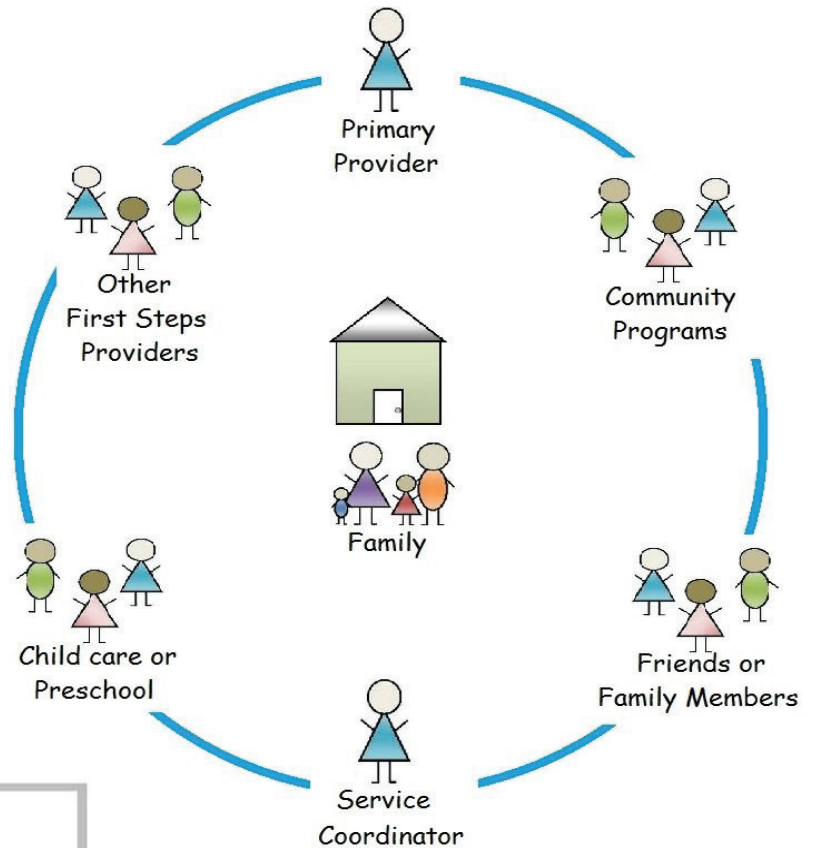
Caleb (left) and Chloe (right) are "happy, healthy 3 1/2 year olds"

By Danielle of Wentzville, MO

## How Does First Steps Make a Difference for Families?

**It's a team effort!** Two teams of people work with the families: the Individualized Family Service Plan (IFSP) team and the Early Intervention Team (EIT). These are separate teams, but some people (including the service coordinator and the primary provider) are on both teams.

**IFSP Team:** Parents are an essential member of the IFSP team. Together with the service coordinator, they select the other members of this team. These may include family members, friends and people who provide services. The IFSP team also chooses the person who will be the primary provider, and this person then becomes a member of the team.



**EIT:** The EIT is the other team that supports the families. EIT members include the service coordinator (SC), a physical therapist (PT), an occupational therapist (OT), a speech therapist (SLP) and a special instructor (SI). The primary provider is a professional from one of these fields.

**Primary Provider:** The primary provider represents the family at regular EIT meetings and shares the child's progress. Together they find answers to the family's questions and new ways to address the family's concerns. The primary provider makes sure that the EIT and IFSP team are working together.

## The Adventures of George

George has had his ups and he has had his downs. The journey we have begun with this child started from the day he was born. We noticed he was not breathing well and threw up all his formula (across the room). We had been to several doctors, and tried numerous different treatments. At 4 months, after gaining only a few ounces since birth, our Pediatrician and ENT decided surgery was the only alternative to correct a condition which was blocking his throat passage with extra tissue. Going into surgery, they both told my husband and I it may take a long time, they did not know what they were going to find and what it would take to fix or even if they could fix it. After surgery he began to grow, thankfully, but by this point he was already behind in his physical and motor development. At the age of 1 we knew it was necessary to get him help, we decided to refer him for a First Steps evaluation and had a speech therapist from the hospital make the referral.

Upon the evaluation, we were not surprised to find he had a distinct delay in physical development and in speech. We began to meet with Beth, our speech pathologist and main provider weekly. We also had a special instructor, occupational therapist and dietician. Through the past year and a half working closely with these wonderful people, George has been able to make some great strides in his development of both communication and spoken language. We have seen a new child emerge as he is actually able to communicate his needs and wants to anyone. His physical development is now back on track with others in his age group.



George playing soccer.

Although George still has some very interesting needs and demands in his life, we are getting ready to transition out of First Steps and into the public school system. I know that without the help and support of this organization, George would have fallen lower and lower on the developmental scales and as a parent, especially one with a background in education, this can be devastating for their early educational experiences. George has always been a loving and carefree child, but with the strength and support of our local team, he can shine in every way.

By Kim of Glasgow, MO

### Parents: Are You Interested in Sharing Your First Steps Story or Ideas?

First Steps wants to hear from parents! Parent participation, feedback, and sharing ideas is important to making sure the First Steps program is making a difference for children and families in Missouri. Here are some ways to get involved:

#### Newsletters

Families participating in First Steps receive a quarterly parent newsletter filled with program information, fun activities, helpful ideas, and parent stories.

#### Regional Meetings

Regional Interagency Coordinating Councils (RICCs) have been organized throughout the state to assist the System Point of Entry (SPOE) with the evaluation of the effectiveness of the First Steps system within the region. RICC membership includes family members of children with disabilities, service providers, community partners, and representatives of programs serving children and families.

#### State Meetings

State Interagency Coordinating Council (SICC) is a group which meets quarterly. The role of the SICC is to advise and assist the First Steps program with the state and federal requirements. Each SICC meeting includes a Mission Moment which allows a First Steps family to share their experience.

#### If parents want to share their story or learn more about getting involved, please:

- \*contact your local SPOE office at (866) 583-2392
- \*email the First Steps program at: [sefirststeps@dese.mo.gov](mailto:sefirststeps@dese.mo.gov)
- \*visit the First Steps website at: <http://dese.mo.gov/se/fs/>
- \*visit the RICC website at: <http://dese.mo.gov/se/sicc/RICCContactInformation.html>
- \*visit the SICC website at: <http://dese.mo.gov/se/sicc/>

## When It's Time to Leave First Steps

After First Steps ends at age three, service coordinators and service providers help families identify community resources so that parents can continue to meet the needs of their children. This process is referred to as Transition from First Steps.

Children leave First Steps every day, moving into Early Childhood Special Education (ECSE) through the local school district or other community programs. Children left First Steps for the following reasons in 2011-12:

| Reason for Leaving First Steps                   | # of Children | % of Exiting Children |
|--|---------------|-----------------------|
| Child turned three years old:                    |               |                       |
| Parent requested referral to ECSE - Eligible     | 2,110         | 60.1%                 |
| Parent requested referral to ECSE - Not Eligible | 374           | 10.7%                 |
| Parent did not request referral to ECSE          | 200           | 5.7%                  |
| Family withdrew from First Steps                 | 338           | 9.6%                  |
| Moved out of state                               | 218           | 6.2%                  |
| Child completed IFSP outcomes                    | 144           | 4.1%                  |
| Unable to contact the family                     | 94            | 2.7%                  |
| Child passed away                                | 30            | 0.9%                  |
| <b>TOTAL</b>                                     | <b>3,508</b>  | <b>100%</b>           |

### Reflections from Brody's Family

The First Steps program helped me to provide my child with a strong foundation of which everything else we have accomplished since that time has been built upon. Living in a rural area, it was not easy to find resources or services that had the capabilities of working with my child in the most natural environment. Through the First Steps program we met Marcia. She was the Speech and Language Pathologist that worked directly with Brody. Marcia was an amazing resource to our family. If we had questions about various strategies or therapies, Marcia was able to find information or direct us to those professionals we needed to make contact with. Being well informed helped us as parents to make the right decisions for our son as an individual rather than just as a person with Autism.

The Individualized Family Service Plan allowed our whole family to be a part of the services that were provided. Brody's diagnosis affected not only him, but all of us. Our complete involvement in his program was crucial to his success. If we had not modified our routines and provided him with a safe and comfortable environment in which he could live and learn, he would not have been able to accomplish what he had as smoothly, or he may not have achieved the level of ability that he is currently performing at. Brody could have had access to the best therapies in the world, but if they did not fit into our lifestyle, they wouldn't have been implemented. It was important to us that the strategies suited our way of living in order that they could be applied to everyday situations. This allowed the therapy to be natural and effortless. If it's too hard and unnatural, a family cannot be expected to be consistent.

We are very grateful for the opportunity we had to receive services from First Steps. We worked with many wonderful and caring individuals. We will always remember the kindness that was shown to us during what could have been a very lonely and daunting time. Although it has been several years since Brody has graduated from the program, the groundwork that was laid during that time has removed the ceiling that was hanging over his potential. Brody is capable of doing whatever he dreams of doing, and he will be successful.

**By Randi of Kahoka, MO**



Brody (right) and his older brother Andrew (left) on a recent family visit to Cahokia Mounds

## First Steps Has Been Growing...

Over the past five years the number of children who are eligible and participating in the First Steps program has grown tremendously! There are a variety of reasons for the continued increase in the number of children participating in the First Steps program, including:

- \* Consistent child find efforts conducted at the local System Point of Entry (SPOE) offices to identify children who may be eligible for First Steps services
- \* A strong statewide network, as evidenced by referrals from all primary referral sources
- \* Comprehensive evaluation and assessment of all five developmental areas: adaptive, communication, cognition, physical and social/emotional skills to determine eligibility for First Steps services
- \* Parent satisfaction with the First Steps program, as evidenced by the annual Family Survey Results

### How Much Does First Steps Cost?

|  | FY08    | FY09    | FY10    | FY11    | FY12    |
|--|---------|---------|---------|---------|---------|
| December 1 Child Count                   | 3,450   | 3,784   | 4,200   | 4,539   | 5,024   |
| December 1 Child Count Yearly % Increase | 7%      | 10%     | 11%     | 8%      | 11%     |
| Total Children Served in FY *            | 7,890   | 8,352   | 9,183   | 9,864   | 10,659  |
| Total Cost per Child **                  | \$3,217 | \$3,925 | \$4,008 | \$4,057 | \$3,770 |
| Direct Service Cost per Child ***        | \$2,369 | \$2,724 | \$2,809 | \$2,886 | \$2,670 |

\* Total number of children who were referred to the program and who had some type of service (evaluation, meeting, direct services, etc.)

\*\* Total cost per child includes all administrative, training and testing costs as well as direct services to children

\*\*\* Direct service cost per child includes only the direct services provided to eligible children under an Individualized Family Service Plan (IFSP)



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