

Year at a Glance

2015-16



What is First Steps?

First Steps is Missouri’s Early Intervention system for infants and toddlers, birth to age three, who have delayed development or diagnosed conditions that are associated with developmental disabilities. First Steps is a voluntary program which provides families the tools they need to help their child be successful. Families play an integral role in their child’s development.

What is a SPOE?

First Steps is operated through contractual agreements in ten regions across the state. The regional offices are known as a System Point of Entry (SPOE) and they provide service coordination, intake and eligibility determination, as well as all local administrative activities for the program. Building a strong network among the SPOE and primary referral sources in a community assists in the early identification and referral of children who are potentially eligible for First Steps. Missouri is a geographically diverse state, yet regardless of location within the state, all Missouri children and families receive support from a SPOE in their area.

What is an IFSP?

Children found eligible for First Steps have an Individualized Family Service Plan (IFSP) which reflects a family’s concerns, priorities and resources with regard to the development of their infant or toddler. Families participate as partners in the planning, development, implementation and review of their IFSP. The IFSP process is unique to each family. Service coordinators and service providers recognize that families are diverse, and collaborate with family members to ensure the development of meaningful goals and related services that assist the family in improving their child’s functioning in everyday routines and activities.

Who is Eligible for First Steps?

Infants and toddlers who have one of the following criteria may be eligible for First Steps:

Newborn Condition	Diagnosed Conditions	Developmental Delay
<p>Referred prior to 12 months of age with a birth weight less than 1,500 grams, with one or more of the following conditions diagnosed at birth or within 30 days post birth:</p> <ul style="list-style-type: none"> • APGAR of 6 or less at 5 minutes • Intraventricular hemorrhage (IVH) (Grade II, III, or IV) • Any Positive Pressure Ventilation greater than 48 hours, including ventilator or oscillator • Resuscitation/code-event requiring chest compressions 	<p>Referred prior to 36 months of age with a diagnosed condition including, but not limited to, the following:</p> <ul style="list-style-type: none"> • Autism Spectrum Disorders • Chromosomal Trisomy • Craniofacial Anomalies • Disorders of the Nervous System • Disorders Related to Exposure to Toxic Substances • Infections/Viruses/Bacteria • Other Chromosomal Abnormalities • Other Genetic/Congenital/Metabolic Conditions • Sensory Impairments • Severe Attachment Disorders 	<p>Referred prior to 36 months of age, with a half-age developmental delay, as measured by appropriate diagnostic measures, in one or more of the following areas:</p> <ul style="list-style-type: none"> • Cognitive development • Communication development • Adaptive development • Physical development, including vision and hearing • Social or emotional development

Eligibility is determined through an evaluation of the child, during which the service coordinator reviews information about the child’s birth, medical history and developmental history. An evaluator may administer a test to determine the child’s abilities. With the parent’s consent, the service coordinator may gather information from caregivers, child care providers, educators or other family members. Eligibility criteria for First Steps, including examples of diagnosed conditions, are available at: <https://dese.mo.gov/special-education/first-steps/eligibility>

Evan's Story:

By Kim of Montgomery City, MO

It is with a thankful heart that I share my son's journey, and the tremendous impact First Steps had on our family. First, I would like to add a little back story. In 2007 I began working as an ECSE teacher. I worked very closely with First Steps coordinators as we transitioned students into the ECSE program. In 2012, I sat in on a First Steps Transition meeting for a young girl with hydrocephalus. I was informed of her medical history, her goals, and her current levels of functioning. I was able to hear about the tremendous strides this beautiful little girl had made over the course of the past three years. Additionally, I left with a pamphlet on hydrocephalus.



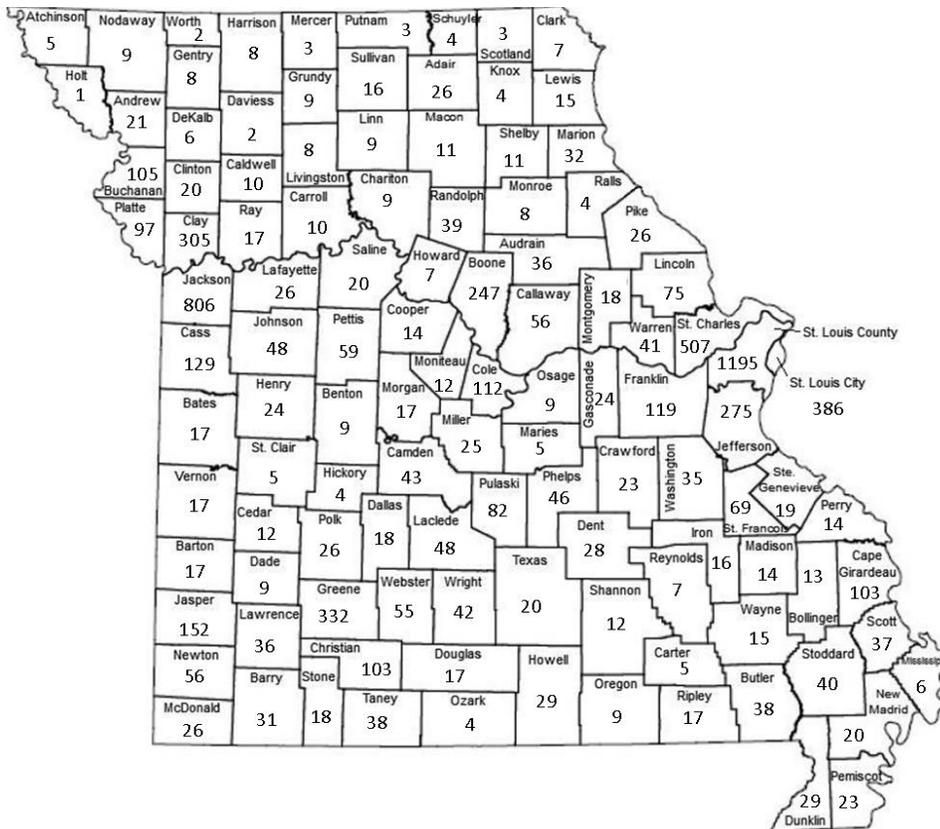
Evan

I had no idea at the time, but I was 3 weeks pregnant. At our 20 week ultrasound we were told that our son had hydrocephalus. We were closely monitored for the remainder of our pregnancy by the Fetal Care Institute at Cardinal Glennon. Once Evan was born, we learned that he has a very rare condition known as Goldenhar Syndrome. In addition to hydrocephalus, Evan was born without his left eye, microtia of his left ear, spinal issues, and moderate to severe hearing loss in his right ear. At birth, the fluid on his brain was so severe, that on CT scans and MRI's, all you could see was a thin ribbon of brain tissue and a huge black void of fluid.

When we left the NICU 4 weeks after Evan's birth, we were given information on First Steps. I was so impressed that this was included in the NICU discharge process. As a teacher I was already fully aware of the impact First Steps has on children. What I didn't realize was the impact First Steps had on the family, and the financial assistance that First Steps provides. The cost of therapy and many assistive technology devices on top of our medical bills would have broken us. Without the assistance that First Steps provides, Evan would NOT be where he is today. Without First Steps, our family would not have been able to afford the assistance Evan so desperately needed. Evan's therapists became an extension of our family, and stayed one step ahead of his needs at all times.

You could say that First Steps has been a part of Evan's journey from the very beginning. From the bottom of my heart, THANK YOU ALL for what you do for our children!

Number of Children Served by First Steps in Each County



Total: 7,069
(May include children over age three who are still receiving services.)

Source: First Steps SPOE Data Report – July 2016. A complete report is available at:
<https://dese.mo.gov/special-education/first-steps/data-budgets-reports>

To Make a Referral to First Steps:

call toll-free (866) 583-2392 or refer online at: www.mofirststeps.com

Who Referred Families to First Steps?

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

Referral Sources in 2015-16	% of Referrals
Medical Providers (Hospitals, Physicians, Other health care, Public health)	38.9%
Parents	37.2%
Social Service Agencies (Mental Health, Health & Senior Services, Children's Division, Domestic Violence and Homeless Shelters)	12.4%
Early Childhood Programs (Parents as Teachers, Early Head Start, School districts, Child care programs)	11.5%
TOTAL	100%

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

In 2015-16, Parents Learned About First Steps From:	% of Parent Referrals
Medical Providers (Hospitals, Physicians, Other health care, Public health)	43.7%
Other (Friend, Family member, Neighbor)	35.8%
Early Childhood Programs (Parents as Teachers, Early Head Start, School districts, Child care programs)	16.9%
Social Service Agencies (Mental Health, Health & Senior Services, Children's Division, Domestic Violence and Homeless Shelters)	3.6%
TOTAL	100%

Annaliese's Story:

By Sharon of Lee's Summit, MO

When my baby was five months old I began to suspect that something was more wrong than just a little delay in development. At eight months we spent a week inpatient at Children's Mercy Hospital. We came home with a list of things crossed off the diagnosis list, a long symptom list, and a surety that the genetic test results would make us cry.

At ten months my baby could not sit up or crawl, and twice when she rolled over she dislocated an elbow. We were on a waiting list for surgery for a feeding tube. I wanted to help my daughter, but I did not know what to do. At our pediatrician's suggestion we began having Missouri First Steps therapists visit our home.

My darling is physically and cognitively impaired. A neurologic disorder affects all aspects of her body. We were seen weekly by Missouri First Steps physical therapy, occupational therapy and speech/feeding therapy, and monthly by a nutritionist and special instructor. These fine ladies taught me how to do therapy with my daughter, and adapted our program to each new situation as my daughter passed through stages where she would not touch carpet or grass, wind in her face or a spoon touching her lip made her vomit, and being put in a crawl position made her scream.

When we began therapy, pushing up to her elbows made her so tired that even though she had slept 14 hours through the night, and only been awake an hour when we began therapy, she would fall asleep after 20 minutes of physical therapy, with the therapist still massaging her legs. After two years of therapy my daughter can drink thickened liquids through a straw, safely eat pureed and soft foods, walk (with an unsteady gait, but still, she can walk), and is a happy and active toddler.

My daughter will never be a "normal" child, but we are now much better prepared to help her reach her potential. We could not have achieved the progress of the last two years without this in-home therapy / parent education program. With three preschoolers, frequent doctor appointments, feeding pump and medicine schedule, and an easily fatigued baby, I could never have kept the therapy schedule allowed by having the therapists come to our home. Because the therapists spent time explaining the purpose of exercises and activities, and demonstrated and then watched and evaluated my attempts at the exercises, I was able to continue therapy exercises on non-visit days as instructed.

Thank you for this program.



Annaliese (far right) and her family

Bryce's Story:

By Amej of St. Peters, MO



Bryce

I am a First Steps parent of an amazing super hero named Bryce. Three years ago an ultrasound found that Bryce was going to be born with a cleft lip and palate. We were so scared and felt completely alone. Bryce was our 3rd child so we knew how hard having a child with special needs was going to be with two other children to care for. We met with our Cleft Team where they explained First Steps to us.

Four months later, Bryce was born and our journey began. His first surgery was set for six weeks later. Within that time, we met our First Steps therapists and they instantly became part of our family.

As an infant, Bryce had feeding and growth issues, our First Steps providers supported Bryce and our family through a stressful time. After Bryce's first surgery his feeding and growth changed. We had become frequent guests at the hospital. Bryce was diagnosed with Failure to Thrive because of the lack of nutrients his body was able to absorb. His situation became severe and medical testing began as we searched for answers.

Ultimately, Celiac's Disease was the reason he was not growing and not absorbing nutrients. At this point, our First Steps providers were committed to helping me help Bryce. Our providers were familiar with Celiac's Disease and they took time to help me understand it more. He has had 10 surgeries including a feeding tube, each one setting him further behind. Our First Steps Dietitian, Speech Therapist, and Special Instructor worked together with our medical team to monitor him closely and made sure we had all the resources we needed. Getting him healthy and growing was the first step. When he was ready for toddler food, the First Steps providers helped me make all of his food from scratch. I became very comfortable making him foods. Finally, he started growing and thriving 7 days on a gluten free diet. Bryce became happy. He laughed and danced for the first time. He was a completely different child. Once he started gaining weight we were able to get to work on his speech and language.

When Bryce transitioned out of First Steps it was difficult for me. The providers had become my friends and have continued to be emotional support for me after First Steps. I am so thankful for Jill Brew, Chris Davis and Jenny Mahon. Now, Bryce is 3 1/2 years old and he is silly, strong and full of smiles. He is growing well and exceeding expectations every day. We are so thankful for the Missouri First Steps Program!

When It's Time to Leave First Steps

Most families leave First Steps when the child turns three years old; but, there are times when families leave First Steps before the child is three. Most children go to Early Childhood Special Education (ECSE) through the local school district or another community program after First Steps. However, some children leave for other reasons such as completing IFSP outcomes before age three or the parent chooses to leave the program.

Reasons for Leaving First Steps in 2015-16	# of Children	% of Exiting Children
Completed First Steps Program:		
Parent requested referral to ECSE - Eligible	2,306	49.9%
Parent requested referral to ECSE - Not Eligible	406	8.8%
Parent did not request referral to ECSE	207	4.5%
Eligibility for ECSE in process	188	4.1%*
Other Reasons:		
Family withdrew from First Steps	731	15.8%
Unable to contact the family	295	6.4%
Moved out of state	251	5.4%
Child completed IFSP outcomes	211	4.6%
Child passed away	25	0.5%
TOTAL	4,620	100%

*Previous Year at a Glance reports included this data under the category of "Parent requested referral to ECSE - Eligible".

Sydney's Story:

By Christy of Jefferson City, MO

Sydney Ann was born on September 7, 2012. We were so elated to have a healthy baby girl join her brother Brock. The pregnancy was uneventful and her arrival went smooth. The joy we had from that first day we laid eyes on her gave us so much hope for her future.

At 6 months of age, I began asking the doctor if he thought she was progressing like she should. I had several friends with babies the same age and Sydney didn't seem to be sitting up as well or eating baby food as easily. At that point, the doctor said he was not concerned.

Three months later Sydney was still not sitting up. The doctor suggested we meet with First Steps and Sydney was found eligible. Bridget Berhorst, occupational therapist and Lisa Borgmeyer, physical therapist and Donna Downing, special instructor entered Sydney's life. We had no idea at that time what an important part of Sydney's life they would be.

On October 13, 2013, Sydney experienced an extended episode of seizures and was flown to St. Louis Children's Hospital and there she was diagnosed with Tay-Sachs disease. The doctor shared with us that there is no cure and no treatment. This disease affects the Central Nervous System and she would eventually lose her sight, hearing, mobility and even the ability to swallow. Most children do not live past the age of 4.

Our first question was what do we do now? The answer was there is no need to make drastic changes until her body tells us. This is when Sydney's First Steps team kicked it into high gear! Bridget, Lisa and Donna spent so much time watching, researching, and exhausting every resource and avenue to get Sydney the best care and support she needed. Our team was rallying and became our biggest cheerleaders, graciously sharing knowledge and resources with us.

As time went on, we began to see the disease take over Sydney's body. She was no longer smiling or laughing. The focus was gone from her eyes but she always knew you were there. The seizures increased. But, her care, treatment and goals still stayed intact with First Steps. They were not going to give up on her!

In early March of 2015, Sydney had a checkup with her pulmonologist. At this appointment, it was discovered that Sydney had pneumonia. This pneumonia was caused by her constant aspiration due to her losing her ability to swallow. We knew her body was starting to give us signs that she was tired. Hospice came in several times a day and helped us prepare. What is the most amazing is how Sydney's First Steps team was there with us the whole time. They were spending the night on the living room floor, taking shifts to help administer medicine, working to keep her body comfortable and knowing what those signs were, and helping our family in more ways than they will ever know.

Sydney passed away in my arms and surrounded by her family on the morning of March 12, 2015. She has left a void that will never ever be filled. We know she is at peace now.

As you can see from this story, First Steps made a huge impact on our lives. The relationships and trust put into Lisa, Bridget and Donna are something that you can't put words to. I can't imagine what our life would be without them. First Steps is literally a priceless program that no one will understand until they have to use it. Thank you so much for all you do for our children!



Sydney (right) and her family

Parents: Are You Interested in Sharing Your Experiences?

Parent participation and feedback are important in helping the First Steps program make a difference for children and families in Missouri. Here are some ways parents can get involved:

- First Steps regional council meetings are held throughout the state to provide an opportunity for parents to share their experiences and participate in discussions with local members.
- First Steps state council meetings are held in Jefferson City to provide an opportunity for parents to share their experiences and participate in discussions with state members.

More information about state or regional councils is available at: <https://dese.mo.gov/sites/default/files/se-fs-sicc-first-steps-icc-brochure.pdf>

Annual Performance Report

Each year the Department of Elementary and Secondary Education (DESE) sends a report to the U.S. Department of Education, Office of Special Education Programs about the performance of the First Steps program. The report contains information on the following Annual Performance Report (APR) indicators:

2016 APR Submission	Statewide Performance	
#1 - Timely Services	97.25%	
#2 - Services in Natural Environments	99.39%	
#3 - Early Childhood Outcomes	Made Progress	Reached Age Expectation
3A - Social Emotional Skills	82.65%	26.81%
3B - Acquiring and Using Knowledge and Skills	84.62%	21.35%
3C - Use of Appropriate Behaviors	84.40%	26.75%
#4 - Family Involvement: First Steps helped the family...		
4A - Know Their Rights	98.64%	
4B - Effectively Communicate Their Children's Needs	96.15%	
4C - Help Their Children Develop and Learn	97.64%	
#5 - Child Find: Birth to Age One of MO Population	1.14%	
#6 - Child Find: Birth to Age Three of MO Population	2.41%	
#7 - 45-Day Timeline	100%	
#8A - Timely Transition Plan with Steps and Services	89.87%	
#8B - Timely Notification to the School District	100%	
#8C - Timely Transition Conference	100%	
#9 - Resolution Sessions	NA	
#10 - Mediation	NA	

The APR includes an indicator for program improvement: Indicator 11: State Systemic Improvement Plan (SSIP). Phase II of the SSIP was submitted to the U.S. Department of Education, Office of Special Education on March 31, 2016. The focus of Phase II is to build the capacity for the state to support the regional system in identifying, implementing and evaluating the use of evidence-based practices. The following is an excerpt from the Phase II report:

Evidence-Based Practices

What are evidence-based practices (EBP) in early intervention? How does one observe them? Can they be measured? While there is ample information about early intervention, practices are not always referred to as “evidence-based,” so it can be confusing and overwhelming to professionals trying to learn about and implement EBP. Professionals need help connecting research to practice to make EBP a reality. Therefore, DESE is currently creating a set of profiles on EBP for early intervention.

The profiles will incorporate existing literature on EBP from national sources, such as the National Association for the Education of Young Children (NAEYC) *Developmentally Appropriate Practices*, the *Division of Early Childhood (DEC) Recommended Practices*, the *Seven Key Principles: Looks Like/Doesn't Look Like*, and the *Agreed Upon Practices for Providing Early Intervention Services in Natural Environments*. The profiles will address practices in three areas: intake visits, IFSP meetings and home visits.

Each profile will include a description of the essential functions and a three-point rating scale to rate the practices. DESE will seek assistance from NAEYC, DEC or other experts in the field of early intervention, as needed. SPOEs will begin using the drafts in late 2016 and DESE will collect feedback in order to revise and finalize the profiles in 2017.

A complete report on the performance of the First Steps program is available at: <https://dese.mo.gov/special-education/state-performance-plan> under Part C - ages Birth to 3 (First Steps).

Provider Fiscal Monitoring

In 2015-16, an estimated 1,500 providers were enrolled in First Steps and approximately 33,000 claims were submitted each month by providers. All First Steps services are subject to federal, state and local audits and provider monitoring. Providers are required to meet and maintain all guidelines and policies of the First Steps program, including proper billing practices.

DESE staff conduct two types of fiscal monitoring activities: scheduled and requested. In the scheduled monitoring activities, DESE selects files and verifies providers are documenting and claiming services in accordance with state guidelines. In the requested monitoring activities, a parent, service coordinator or another provider contacts DESE with concerns about a provider's billing and DESE staff review documentation related to the provider's payment.

For both types of monitoring activities, DESE staff review the service authorization and progress notes to verify there is sufficient documentation to support payment to the provider. The following chart shows the results of provider monitoring activities in 2015-16:

Type	Activity	FY 16 Reviews	Passed Review*
Scheduled/ Monthly Review	Timely Claim Submission <i>(Provider submitted claim late, over 60 days from the date of service)</i>	196,862 claims	98.9%
Scheduled/ Monthly Review	Hours Billed in a Day <i>(Provider claimed more than 10 hours in one day)</i>	1,119 claims	98.9%
Scheduled/ Quarterly Review	No-Show Visits in a Month <i>(Provider claimed more than three visits in one month)</i>	399 claims	99.9%
Requested/ As Reported	Reported Billing Issues <i>(Someone reported a concern with a provider's payment for services)</i>	24 reports	50%

* When a claim fails a review, funds are recovered from the provider for inadequate documentation to support payment for the service.

First Steps Child Count and Cost

	FY12	FY13	FY14	FY15	FY16
December 1 Child Count *	5,024	4,999	4,988	5,388	5,928
December 1 Child Count Percent of Change	11%	-0.5%	0%	7.5%	9.2%
Total Children Served in FY **	10,659	11,194	11,613	12,720	13,945
Total Cost per Child ***	\$3,770	\$3,374	\$3,243	\$3,100	\$3,043
Direct Service Cost per Child ****	\$2,670	\$2,380	\$2,294	\$2,251	\$2,188

* Total number of children with an active IFSP on December 1

** Total number of children who had some type of First Steps service (evaluation, IFSP meeting, or direct service)

*** Total cost per child including administrative, training, testing and direct service costs

**** Direct service cost per child including evaluation, IFSP meeting, direct service and mileage



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