



Year at a Glance 2017-18



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. The federal law governing First Steps is Part C of the Individuals with Disabilities Education Act (IDEA). The Department of Elementary and Secondary Education (DESE) is the lead state agency responsible for implementing the First Steps program.

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 office is known as a System Point of Entry (SPOE). The SPOE employs approximately 140 Service Coordinators who 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.

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• Social or emotional development• Physical development, including vision and hearing

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>

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 2017-18	% of Referrals
Medical Providers (Hospitals, Physicians, Other health care, Public health)	41.7%
Parents	37.1%
Social Service Agencies (Mental Health, Health & Senior Services, Children's Division, Domestic Violence and Homeless Shelters)	9.6%
Early Childhood Programs (Parents as Teachers, Early Head Start, School districts, Child care programs)	11.6%
TOTAL	100%

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

In 2017-18, Parents Learned About First Steps From:	% of Parent Referrals
Medical Providers (Hospitals, Physicians, Other health care, Public health)	48%
Other (Friend, Family member, Neighbor)	32%
Early Childhood Programs (Parents as Teachers, Early Head Start, School districts, Child care programs)	16%
Social Service Agencies (Mental Health, Health & Senior Services, Children's Division, Domestic Violence and Homeless Shelters)	4%
TOTAL	100%

Jonah and Gideon's Story:

By of Sharon of Dexter, MO

I sat with my husband, a psychiatrist across from me, and our non-verbal son behind her repetitively opening and closing her cabinet door. She explained our little boy has autism, I couldn't contain my tears. She said he is the same little boy that I brought in and I informed her while that is true, his momma is a now a different person. I took on the role of a "special needs" parent. She tells me to call First Steps. My husband and I walked out feeling helpless.



"Brotherly love" - Sharon

I phoned First Steps and after the evaluation, Jonah was set up with services. Slowly we chipped away at him and watched this amazing boy bloom. We watched as his speech slowly took off.

Months later our youngest son was born 7 weeks early. My doctor came into the room and informed us "we think your baby has Trisomy 21." Around our third week in the neonatal intensive care unit (NICU) the social worker brought me a packet. I laughed a bit when she talked about First Steps and how they could help us with Gideon. I explained we had experienced First Steps through our older son.

This past May, we had Jonah's final IEP meeting at school. Jonah no longer qualifies for Early Childhood Special Education (ECSE). We would not be here today without early intervention. Today, Gideon is 2 ½ and transitioning to ECSE. I am so thankful for our time with First Steps and the relationships we made. Our team became our family. I encourage any parent with a child that shows delays to contact First Steps.

When Jonah started therapy, my oldest son Silas was getting out of the car one day and said to me, "Mom, I can do all the things I can do. I can do all the things!" That little phrase is our family motto, "You can do all the things you can do."

Luke's Story:

By Kristi of Marshfield, MO

My husband, Jason, and I were first introduced to the First Steps program by a social worker in the hospital where our adopted son, Luke, was born in September of 2014. Luke had no prenatal care, was born with club foot, and was exposed to drugs and alcohol. Neither of us had heard of the First Steps program before and we, unfortunately, left the hospital without realizing what invaluable services they would one day provide for our family.

Well, as those first weeks at home turned into months, it became more and more apparent that Luke was not developing as expected. As he approached his first birthday, he was unable to sit on his own, hold a bottle, babble, or eat solid foods. It was then that a friend of ours also recommended calling First Steps.

So, we called and were amazed at how we were assigned to a coordinator in our area that worked to get an evaluation done and services set up for Luke so quickly! Each of the therapists have been a huge help and so supportive in striving to work together to ensure the best possible outcomes for Luke.

They are the ones who made referrals for us to have his hearing and vision checked, to have a pediatric specialist evaluate him, to educate us on primitive reflexes, give us ideas for feeding and how to overcome sensory issues, and who made sure he had the equipment he needed to start walking. The list could just go on and on. It was from their referrals that we were finally able to find out what was causing all of his delays, rule out genetic issues, and get the services he so desperately needed!

Luke was diagnosed with Cerebral Palsy and Autism. Since the First Steps team of therapists intervened, Luke's progress has been amazing. It's hard to even express in words how thankful we are for this remarkable group of people who have poured their hearts into our son's life these past two years!



"Luke is all smiles" - Kristi

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 2017-18	# of Children	% of Exiting Children
Completed First Steps Program:		
Parent requested referral to ECSE - Eligible	2,697	51.0%
Parent requested referral to ECSE - Not Eligible	511	9.6%
Parent did not request referral to ECSE	280	5.3%
Eligibility for ECSE in process	178	3.4%
Other Reasons:		
Family withdrew from First Steps	791	14.9%
Unable to contact the family	286	5.4%
Moved out of state	270	5.1%
Child completed IFSP outcomes	252	4.8%
Child passed away	25	0.5%
TOTAL	5,290	100%

Gage's Story:

By Hannah of Springfield, MO

Our family has a deep love and appreciation for the First Steps program. It was such a blessing to us for Gage's first three years in countless ways. After Gage was diagnosed with congenital cytomegalovirus (CMV), we were quickly connected with a service coordinator and began receiving Occupational Therapy (OT) early on.

Therapies increased with time, from monthly visits that became weekly, and not just OT but Physical Therapy and Speech as well. Shortly after Gage's first birthday, we moved and were introduced to new therapists who covered our region.

Each and every person we worked with at First Steps was absolutely wonderful. They not only cared about Gage reaching his goals, they cared about him as a person. They were his cheerleaders, advocates, and biggest fans. They went above and beyond, thinking outside the box and willing to meet with doctors and daycares, all to make sure Gage was cared for in the best way possible. Their care extended beyond Gage's outcomes and included kindness and compassion shown to me as his mom, for which I'll always be grateful.

My gratitude for First Steps was present each step of the way, but now that services have ended, I'm even more aware of how wonderful their model is. Therapy in the home with parent involvement is huge! I can't imagine how much harder our early journey would have been without First Steps.

It has helped us immensely in a variety of ways—financially, emotionally, practically and so much more. Gage's first sitter was a connection from our OT. Our service coordinator gave us a new perspective on school districts. Therapists have lent a helping hand and been a shoulder to cry on. I could go on, but I'll end by simply saying the words that will never feel like enough—thank you!



"Family fun" - Hannah

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. If you currently have a child in the First Steps program or your child previously participated in the First Steps program, here are two ways you can share your experiences:

- 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.

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

For more information, contact your Service Coordinator or local SPOE office at: (866) 583-2392

Annual Performance Report

Each year 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:

2018 APR Submission	Statewide Performance	
#1 - Timely Services	96.04%	
#2 - Services in Natural Environments	99.41%	
#3 - Early Childhood Outcomes	Made Progress	Reached Age Expectation
3A - Social Emotional Skills	88.36%	22.57%
3B - Acquiring and Using Knowledge and Skills	90.03%	17.04%
3C - Use of Appropriate Behaviors	90.09%	22.66%
#4 - Family Involvement: First Steps helped the family...		
4A - Know Their Rights	98.53%	
4B - Effectively Communicate Their Children's Needs	96.80%	
4C - Help Their Children Develop and Learn	97.60%	
#5 - Child Find: Birth to Age One of MO Population	1.33%	
#6 - Child Find: Birth to Age Three of MO Population	2.87%	
#7 - 45-Day Timeline	98.21%	
#8A - Timely Transition Plan with Steps and Services	92.59%	
#8B - Timely Notification to the School District	100%	
#8C - Timely Transition Conference	98.75%	
#9 - Resolution Sessions	NA	
#10 - Mediation	NA	

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).

Tobias' Story:

By Cindi of Union, MO

Tobias was born at 31 weeks and weighed 2 pounds 8 ounces. We spent 86 days in the NICU with him and he had two surgeries, many tests and procedures. Not long after we came home we started with First Steps.

When we began, Tobias couldn't hold his head up, hold a toy or even drink from a bottle. He vomited 15-20 times a day. With the help of our First Steps providers, Tobias can hold up his head, roll from his side, activate toys using his Big Mack Switch and is starting to sit up unassisted. Seeing him play with toys is one of the greatest feelings. Tobias received a diagnosis of ATR-X at 1 ½ years. There are less than 200 cases in the world and none of his doctors had heard of it. My husband and I felt lost. Our First Steps providers were so helpful and understanding. They helped us to see Tobias was just as amazing after his diagnosis as he was before.



"Family celebration" - Cindi

First Steps helped us with feeding issues, speech concerns, and provided Tobias with equipment we needed to help Tobias be successful. We tried many formulas for Tobias and our First Steps provider was able to help us find the right one. His vomiting decreased to only 0-3 times per day.

Over the past two years, we have seen our sweet baby turn into a strong, fierce, amazing little boy. He is very social and loves everyone and shows no fear. I wish he could stay in First Steps forever. Thank you for all that you do. We love you!

The Number of Children in First Steps Continues to Grow

The First Steps program, with the assistance of Phillips and Associates, Inc., conducted a study in 2018* of census population and prevalence measures to determine the number of children projected to be eligible for services.

This study identified the number of children eligible for First Steps services has grown in the past five years, a trend consistent with previous studies in 2007 and 2012.* These studies found the number of children eligible for First Steps services increased from 1.47% to 2.88%, when compared to the Missouri birth to three population. The 2018 study also projected growth in First Steps will continue for the next five years.

While the amount and type of growth varies by region and eligibility category, the reasons for growth are common across the state of Missouri. The 2018 study indicated some factors influencing an increase in children with developmental delays or disabilities include: improved diagnostics and survival of newborns, increased screening activities for infants and toddlers, and more children experiencing developmental delays due to toxic substances such as prenatal drug exposure and neonatal abstinence syndrome.

* To review the 2007, 2012 and 2018 studies on First Steps Eligibility Review and Forecasting, visit the Missouri First Steps Research and Demonstration Projects website at:

<https://dese.mo.gov/special-education/first-steps/first-steps-resources#Missouri Research>

First Steps Child Count and Cost by Fiscal Year (FY)

	FY15	FY16	FY17	FY18
Total Children Served*	12,720	13,945	14,472	15,333
Increase in Children Served	8.7%	8.8%	3.7%	5.6%
Total Cost per Child**	\$3,100	\$3,043	\$3,133	\$3,079
Total Program Expenditures	\$39,431,388	\$42,435,974	\$45,903,614	\$47,205,270
*Total number of children who had at least one First Steps service (e.g., evaluation, IFSP meeting, direct service)				
**Total cost per child includes administrative, training, testing and direct service costs				

A complete report on the First Steps budget is available at: <https://dese.mo.gov/special-education/first-steps/data-budgets-reports> under Financial Reports.



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