

25
ANNIVERSARY
Missouri
First steps
EARLY INTERVENTION



YEAR AT A GLANCE: 2018-19

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 10 regions across the state. The regional office is known as a System Point of Entry (SPOE). The SPOE employs approximately 170 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 2018-19	% of Referrals
Medical Providers (Hospitals, Physicians, Other Health Care, Public Health)	47.7%
Parents	36.6%
Early Childhood Programs (Parents as Teachers, Early Head Start, School Districts, Child Care Programs)	11.0%
Social Service Agencies (Mental Health, Health & Senior Services, Children's Division, Domestic Violence and Homeless Shelters)	4.7%
TOTAL	100%

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

In 2018-19, Parents Learned About First Steps From:	% of Parent Referrals
Medical Providers (Hospitals, Physicians, Other Health Care, Public Health)	47.2%
Other (Friend, Family Member, Neighbor)	32.6%
Early Childhood Programs (Parents as Teachers, Early Head Start, School Districts, Child Care Programs)	17.2%
Social Service Agencies (Mental Health, Health & Senior Services, Children's Division, Domestic Violence and Homeless Shelters)	3.0%
TOTAL	100%

Jaxon's Story:

By Courtney of Lonedell, MO

Jaxon's diagnosis is Spastic Quadriplegic Cerebral Palsy. Jaxon has been with the First Steps program since he was 3 months old. We were first introduced to Tegan his service coordinator along with Tricia & Anne. These three women have been our rocks since the beginning. We were then introduced to Hannah after Jaxon turned one and Sha'Rona after Jaxon turned two; they all have fallen into sync with our family. Jaxon receives Special Instruction, PT, & OT.



"Crusing along" - Courtney

I can't say enough wonderful things about the care Jaxon has received on top of how much each of these ladies stay completely involved with us from outside appointments/surgeries to celebrating his milestones. Anytime my parents (Jaxon's Nana & Papa) or myself have any questions or an off the wall idea they listen and collaborate with us. Everyone has taken the time to explain all the new equipment to Jaxon's entire tribe of caregivers because, while I'm at work my parents care for Jaxon. It has been so important that everyone is on the same page with what he needs to be doing to continue to improve.

I am happy to report Jaxon can sit unassisted up to 30 mins now, knows over 50+ words, can feed himself by hand, stand while assisted, tolerate being put into what used to be very uncomfortable positions and is even working on potty training which is huge! I am forever grateful for these women who have been placed in my life and my son's life. We have been so touched by all of their kind words and all the

hope they have continued to give us. Most importantly none of them have EVER given up on Jaxon being successful!

Thank you for all that you have done, all that you do and all that you'll continue to do until we have to say goodbye at three. I'm sure there will be tears, lots of hugs and love. You have made our scary world into a much brighter place!

Gracelynn's Story:

By Rebecca of Cape Girardeau, MO

We have had nothing but a great experience with First Steps! Our journey started when Gracelynn was 7 months old and was placed in our house via foster placement with her siblings. She was drug exposed at birth and had spent much of her early months in the NICU and at another foster placement due to withdrawing from the drugs that were in her system.

As soon as she was placed in our care we were immediately contacted to continue the First Steps Program that had already been started at her other placement before us. Gracelynn was showing signs of failure to thrive, being developmentally behind and showing weakness on her right side and very weak motor and social skills.

Ms. Debbie, Diane, Carisa and Lani had been with Gracelynn from the beginning and brought myself and my husband up to speed on what they were seeing and what steps we could take as a family to help Gracelynn catch up to where she should be based on her age. Not only did Gracelynn start meeting her goals, she started exceeding them!



"In this together" - Rebecca

We have since adopted Gracelynn, along with 2 of her other sisters. Gracelynn was able to start the Early Childhood Program this year and we have since seen nothing but major strides of improvement, none of that would be happening without the ground work that was laid with First Steps.

We are so appreciative and thankful that there is a program like First Steps that teaches parents and children how to reach the goals they need to in order to succeed. We are forever grateful for the help that we received and have no doubt in our mind Gracelynn will continue to thrive and exceed the expectations laid out before her due to the ground work of First Steps. Thank you again so much!

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:

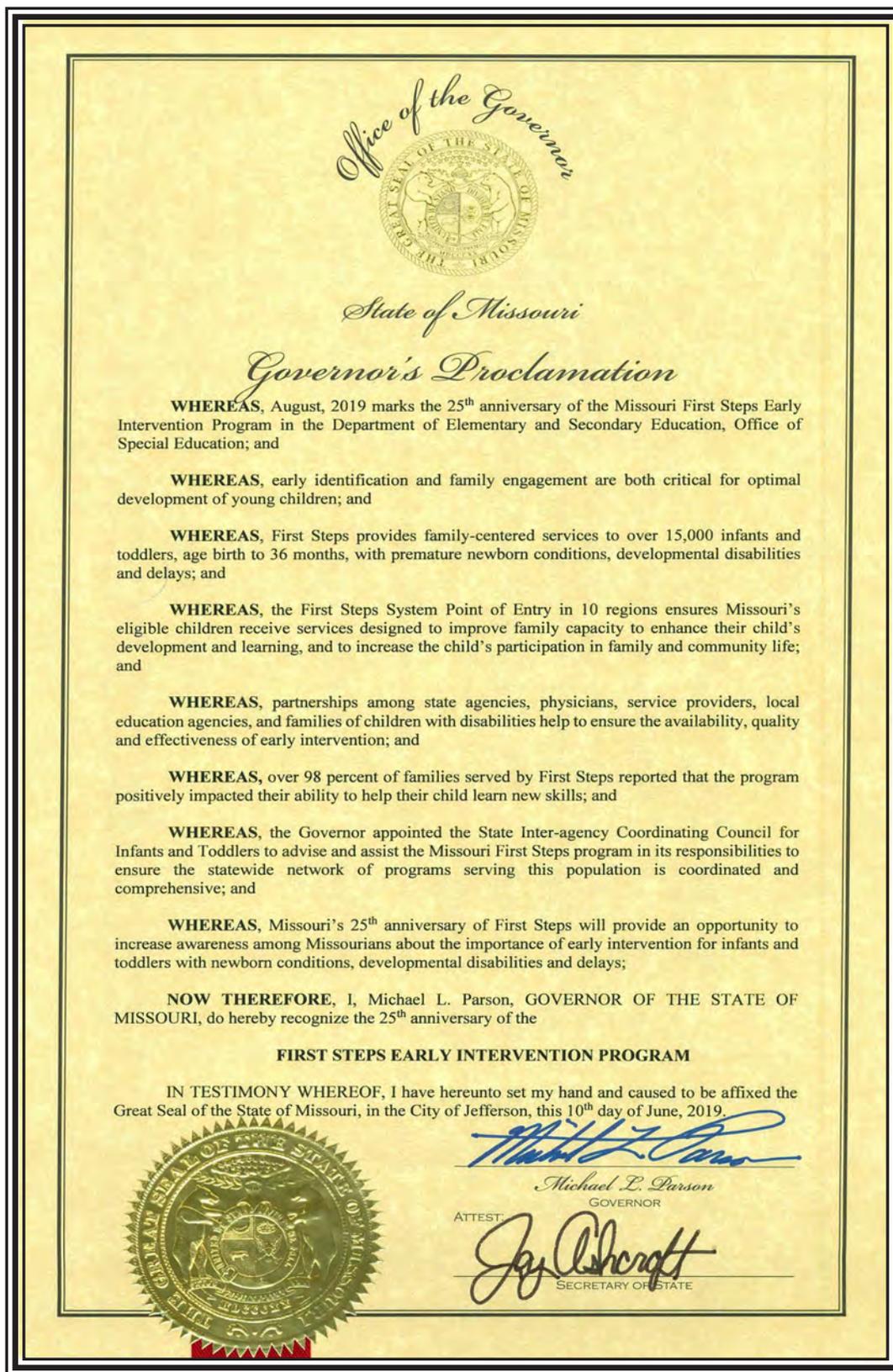
2019 APR Submission	Statewide Performance	
#1 - Timely Services	97.30%	
#2 - Services in Natural Environments	99.39%	
#3 - Early Childhood Outcomes	Made Progress	Reached Age Expectation
3A - Social Emotional Skills	90.28%	21.26%
3B - Acquiring and Using Knowledge and Skills	91.53%	16.37%
3C - Use of Appropriate Behaviors	91.17%	20.20%
#4 - Family Involvement: First Steps helped the family...		
4A - Know Their Rights	99.30%	
4B - Effectively Communicate Their Children's Needs	98.60%	
4C - Help Their Children Develop and Learn	98.83%	
#5 - Child Find: Birth to Age One of MO Population	1.33%	
#6 - Child Find: Birth to Age Three of MO Population	2.95%	
#7 - 45-Day Timeline	98.28%	
#8A - Timely Transition Plan with Steps and Services	93.75%	
#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).



August 2019 marks 25 years of early intervention services in Missouri. In 1986, former Governor of Missouri John Ashcroft appointed DESE as the lead agency for Part H of the Education of the Handicapped Act, now known as Part C of the IDEA. First Steps started as a small pilot program in Missouri before going statewide in August 1994.

Governor Mike Parson issued the following proclamation in June 2019, recognizing the importance of early intervention services and this milestone for the early intervention program.



Elijah's Update:

By Elijah Mayfield of Jefferson City, MO

My name is Elijah Mayfield. I am 23 years old. I live in Jefferson City, Missouri with my mom and dad (Pam and Todd). I have a 19 year old sister, Hannah, who attends College of the Ozarks. I have been serving as an intern in the Missouri Governor's Office since December 2014. I work as a courier where I process, sort and deliver important documents for the Governor and his staff. I love my job because I get to interact with a lot of different people throughout the capitol building and in various state office buildings.



Elijah participated in First Steps as a toddler

In March 2018, then Governor Eric Greitens appointed me to the Governor's Council on Disability. I am the first person with Down syndrome to ever be appointed to a commission by a Missouri governor. I also work as a volunteer at SSM Health-St. Mary's Hospital. My favorite part about serving at the hospital is getting to work in a variety of positions where I am learning different job skills while also getting to help others.

I also serve as the head manager for the Lincoln University men's basketball team. I assist the coaches and players by running the shot clock during practices and help take care of the equipment and uniforms. That includes staying after practice and games to wash, dry, fold and hang all the uniforms and gear. I love this job because I get to hang out with the team and coaches every day during the season. They have become some of my best friends.

I love all my jobs because they each provide an opportunity to serve in a unique way and every day is a great opportunity to show people that people with Down syndrome have a lot to offer and can serve in many different capacities. You can learn more about me by visiting my website: <http://elijah.net>



Elijah with Gov. Mike Parson and Lt. Gov Mike Kehoe

A Provider's Story:

By Zachary Higgs of St. Louis, MO



Zachary as a toddler

January 9, 1991 was the beginning of one of the most hard fought journeys my family would ever experience. I was born with a diagnosis known as Neonatal Hyperparathyroidism, which led me to spend the first five months of my life in the NICU at St. Louis Children's hospital. While in the NICU, I spent most of my time on a ventilator and received a G-tube. Many of the doctors came to the same conclusion, which was that I had a slim chance of surviving. The doctors explained to my parents that the best approach would be to try to enroll me in some type of therapeutic program in the upcoming future.

In July of 1991, I started receiving First Steps services from St. Louis Regional Office. Through First Steps I was able to receive Speech, Occupational, Physical and Developmental therapies. My delays were across a variety of different developmental areas, which included not being able to speak or walk without a walker for the first few years of my life. The delays/difficulties were not just related to speaking and walking, I also had a variety of different sensory difficulties and was G-tube fed until I was two years old.

If it were not for First Steps and the therapists that worked with me, I'm not sure I would have come as far as I have in life. I have a Master's degree in Behavior Analysis and am now working as a Behavior Analyst for First Steps. I truly love the families that I work with and believe that First Steps is extremely important when it comes to providing helpful tools/strategies for both children and their families. The most important advice I give to each family I work with is that they should never give up and fight for every opportunity they get to make sure their child receives the greatest possible support in order to live the best life possible. If it weren't for my family and the amazing support system, I would never have been able to give back to future families.



Zachary, with his mother, receiving an award



ANNIVERSARY

The annual First Steps family survey helps DESE evaluate the quality and effectiveness of First Steps services. By sharing their perspectives, families help to improve the program.

"We absolutely loved First Steps. They did so much for our family and our little boy that we will always be grateful. Without them our son would even be more delayed. I wish we could have continued with our therapists because they are like family. I recommend First Steps to any family."

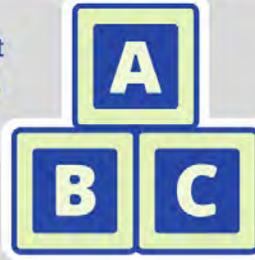
"First Steps has been a saving grace for our son and family. Our primary provider has given us the education and tools to best support his growth. This is an amazing program and we wouldn't know what to do without. Thank you for offering this service."

"My First Steps team is exceptional! They have been a huge advocate in getting my son the resources that he needs to thrive. Without this program, my son would not be where he is today in his development. I feel incredibly blessed to had been introduced to this program."

PERCENTAGE OF PARENTS WHO AGREED*

My primary provider in First Steps helps me teach my child.

99.2%



My First Steps providers work with me to help my child in everyday activities.

98.5%

I am able to help my child learn new skills because of First Steps.

98.3%



I feel I am an active part of the team when we meet to discuss my child.

99.1%

*Agreement rate calculated by totaling strongly agree and agree responses in the 2019 Family Survey results

"Thank you for your services and continued support for me and my daughter. This program made a big impact on our lives. My First Steps team will forever be in my heart. Thanks again for making our days brighter through such a trying time."

"The First Steps Program was and is a blessing for not only our child but for us as parents. They gave us the confidence and support to help our premature baby grow into a strong and happy toddler."

"We have been so happy with the program. We feel the early intervention he is receiving now will help him catch up with his peers and be at the right level once he reaches school age. Thank you for the continued support of such an important program."

Bryce's Update:

By Brian and Amey of St. Peters, MO

We are so grateful to Missouri First Steps for the success of our son, Bryce. Bryce was born with a unilateral cleft lip and palate and has endured several surgeries and hospital stays in his short 7 years. Our First Steps team instilled in Bryce a strong work ethic, taught him to be a young self-advocate and they helped empower us as parents every step of the way.



Bryce at 2 days old

Since our last update to Missouri First Steps in 2016 Bryce has moved onto Elementary school with ease. Our team of therapists pointed us towards helpful resources that educated us on the very intimidating world of Special Education. Thankfully, Our FS team referred me to the Parent Information Center for Missouri (MPACT) for additional support. I applied for a position and was hired in 2014. They help empower parents to effectively advocate for their children's unique educational needs. I have gained so much knowledge and experience and can now assist other parents walking through this time of transition.

In First grade, Bryce did not qualify for an IEP for speech. This was a terrifying moment for us. With the ongoing surgeries that Bryce will have through adulthood, the thought of not having speech services at school paralyzed us with fear that he would regress. I reached out to my co-workers at MPACT and they helped me understand that this meant SUCCESS for Bryce and not FAILURE. I have learned that as a parent of a child with unique needs that sometimes fear can steal victory from us. It was an eye-opening moment for us and we celebrated his accomplishments as a family.

Bryce is a very active boy with a smile that can lift the heaviest of hearts. He is currently participating in the SPECTRA program at school and is really excelling in his academics. He is a hard worker academically and he passionately discusses his findings in coding and science classes with all who will listen. He is extremely social and active in sports and extra-curricular activities with no hindrance from his speech. He is healthy and strong and continues to overcome adversity.



Bryce, now 7, after extensive craniofacial procedures

Thank you, Missouri First Steps for helping empower not only Bryce but our entire family!

A Provider's Story:

By Melissa Knetzer of Springfield, MO

Anxious. Apprehensive. Confused. These are words I hear from many families whether it is their first visit with me as a First Steps family or as they look ahead to their child's transition to Early Childhood Special Education (ECSE). I work as a special instructor for First Steps and provide support to families who need evening appointments, because during the day I support students and families in the ECSE program. I have the opportunity to share with my First Steps families my knowledge of ECSE and the process to help ease their concerns and provide them with an understanding of what is involved in the transition to school.

As a First Steps special instructor, I see the benefits of early intervention first hand with children who have developmental delays. We make a positive impact across developmental domains, including language/communication, cognitive development and social/emotional development. These skills provide a foundation for the child as they grow and transition to a school setting.

One example is a child whom I served was non-verbal, exhibited delays in play skills, and had restricted food preferences. With early intervention, we were able to get him to where he would eat with a utensil, use a form of communication to request, and actively engage in appropriate toy play for a period of time. These skills provided him with a strong foundation as he entered the ECSE program to begin his educational journey.

First Steps and ECSE work together to support the families and ensure they are comfortable during the transition from one program to the other.

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

The Ready Family:

By Luke and Kara of Taos, MO

We had our first son Henry 5 years ago with a pretty routine pregnancy and delivery. Henry began to show signs of development delay between 6-9 months when he couldn't hold his head up or sit up unsupported. We self-referred to First Steps. Henry qualified which was shocking in itself to us but we knew we had to try something and start somewhere. He began having PT/OT services.

We were given the life changing diagnosis of Lissencephaly shortly after his first birthday. We were devastated and lost, given the doctors prediction that Henry would have a shortened lifespan of 2-10 years and would likely never accomplish more developmentally than where we were at that time (13 months old) with a baby that couldn't sit, eat on his own or speak.

The First Steps team became our Lifeline and helped pick us up and find direction in this crazy, confusing, and stressful time. They showed us time and time again to not lose hope even with everything stacked against Henry. They went above and beyond to find or make tools that helped Henry and his specific needs and showed us ways to incorporate therapy into Henry's everyday life.

They introduced us to the Special Learning Center (SLC) for classroom and this was another life changing step for us. Henry going to the SLC and having his therapy integrated in his classroom was just one more way they helped guide us and give Henry every opportunity available to become the best version of himself. The First Steps team was our first source of support in a time that was the hardest we had ever faced and they have lifted us up time and time again and provided support for Henry and our entire family. Henry is now walking in a walker independently and has even taken over 100 steps independently. He has over 70 words and is the most social and loveable boy you will ever meet. His smile and laugh is contagious.

Five years later we welcomed our second baby into this world. She decided to make an early appearance, eight weeks, and earned herself a 31 day NICU stay. We are now utilizing First Steps again for our 10-month-old baby girl, Rose. We are fortunate to be able to utilize the same First Step therapists for her that her big brother Henry works with and they have really become part of our family. Her needs are very different and not nearly as intensive but the therapists once again have become our guides to help her gain as much as she can. We just want to say "Thank you" and we are so appreciative that we have these services available to use.



"Graduation celebration!"
- Kara

Kate and Lily's Story:

By Rebekah of Perry, MO

My husband Wes and I will always remember November 25, 2015, as truly one of the scariest days of our lives. While talking over dinner, my water broke nearly two months prematurely with our twin daughters, Kate and Lily.

Fast forward less than 24 hours later and I had been flown to Barnes Hospital in St. Louis and delivered the girls via C-section. I held my little girl's fingers and told them I loved them. They were rushed off to NICU and the next days were a whirlwind of emotions. We didn't know what to expect since the girls had come so early.

After a few months in the NICU, we were able to go home. While in the hospital, we learned our girls may have delays in their growth and development due to prematurity. We were so thankful to receive services through Missouri First Steps.



"Family time" - Rebekah

We are happy to say through all the hard work and persistence of our First Steps providers and Service Coordinator, Kate and Lily has learned to crawl, walk and talk. Our First Steps team has surrounded our family with love, support and even a shoulder for countless tears of joy and frustrations that come along with working to achieve goals.

We have been blessed to have a great group of providers surrounding our family and specifically our amazing daughters. I don't know if we would be as far along had it not been for their constant care at each visit and reassurance we were doing exactly what we needed to be doing for the girls. We will be finishing up our journey with First Steps soon. We will miss everyone and will never forget what a blessing they were to us these last three years. We have faith that Kate and Lily will continue to have success and meet new goals and milestones as they begin the next journey in their lives!

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 2018-19	# of Children	% of Exiting Children
Completed First Steps Program:		
Parent requested referral to ECSE - Eligible	2,812	49.6%
Parent requested referral to ECSE - Not Eligible	595	10.5%
Parent did not request referral to ECSE	297	5.2%
Eligibility for ECSE in process	162	2.9%
Other Reasons:		
Family withdrew from First Steps	892	15.7%
Unable to contact the family	391	6.9%
Moved out of state	258	4.5%
Child completed IFSP outcomes	242	4.3%
Child passed away	25	0.4%
TOTAL	5,674	100%

SPOE Contracts Renewed in 2019

To be compliant with state law for competitive purchasing, DESE works with the State of Missouri, Office of Administration (OA) to rebid the regional SPOE contracts for First Steps services every five years. On April 22, 2019, OA awarded contracts to the agencies listed below through this rebid process for the period of July 1, 2019 through June 30, 2024. There were no changes from the agencies that held the previous SPOE contracts; however, due to the growth in children served in the program, the number of Service Coordinators serving families in Missouri increased from 140 full-time employees (FTE) in the previous contract to 169.5 FTE.

Region	Agency
St. Louis City/County - Regions 1 & 2	A.W. Holdings LLC
Northeast - Region 3	The Dahlberg Group, LLC
Kansas City/Northwest - Regions 4 & 5	The Dalton Group, Inc.
Central - Region 6	Center for Human Services
Southwest - Region 7	Jasper County Sheltered Facilities Association
South Central - Region 8	Abilities First
East Central - Region 9	Center for Human Services
Southeast - Region 10	Education Solutions Consulting

In addition to service coordination, intake and eligibility determination, the contract requirements for the next five-year period include an emphasis on: (1) using data to inform training activities, (2) completing annual needs assessment activities, (3) conducting observations of Service Coordinators to ensure the use of evidence-based practices with families, and (4) improving the parent response rate in annual surveys to families.

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

	FY16	FY17	FY18	FY19
Total Children Served*	13,945	14,472	15,333	15,991
Increase in Children Served	8.8%	3.7%	5.6%	4.3%
Total Cost per Child**	\$3,043	\$3,133	\$3,079	\$3,137
Total Program Expenditures	\$42,435,974	\$45,903,614	\$47,205,270	\$50,158,786
*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.



205 Jefferson St. P.O. Box 480
 Jefferson City, Mo. 65102-0480
 Phone: 573-522-8762 Fax: 573-526-4404
 E-mail: sefirststeps@dese.mo.gov

Website: <https://dese.mo.gov/special-education/first-steps>

