

# Annual First Steps Family Survey

## Statewide Summary

Mailed out by CFO April 2009

Total surveys mailed out: 3898

Number of surveys returned: 1043

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1. How old is your child?					
105 (10.07%)	304 (29.15%)	520 (49.86%)	111 (10.64%)	3 (0.29%)	
Less than one year	1 yr - less than 2 yrs	2 yrs - less than 3 yrs	3 years and over	Did not answer	
2. At what age did your child first begin receiving First Steps services?					
547 (52.44%)	295 (28.28%)	176 (16.87%)	1 (0.10%)	24 (2.30%)	
Less than one year	1 yr - less than 2 yrs	2 yrs - less than 3 yrs	3 years and over	Did not answer	
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4. It was easy to learn about First Steps.					
440 (42.64%)	476 (46.12%)	88 (8.53%)	28 (2.71%)	8	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
5. It was easy to find out if my child was eligible for services.					
479 (46.28%)	490 (47.34%)	56 (5.41%)	10 (0.97%)	5	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
6. It was easy to obtain the services that are needed for my child and family.					
504 (48.70%)	439 (42.42%)	61 (5.89%)	31 (3.00%)	6	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
7. No unnecessary services were included in the IFSP.					
584 (57.37%)	423 (41.55%)	6 (0.59%)	5 (0.49%)	18	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
8. When my child was evaluated, all concerns about my child's development raised by me and others were addressed.					
637 (61.25%)	376 (36.15%)	18 (1.73%)	9 (0.87%)	2	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
9. The results of my child's assessments or evaluations were explained to me in ways I understood.					
613 (59.28%)	400 (38.68%)	14 (1.35%)	7 (0.68%)	6	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
10. I received information and explanations about our family's rights to file a child complaint.					
523 (52.62%)	396 (39.84%)	57 (5.73%)	18 (1.81%)	34	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
11. I received information and explanations about our family's procedural safeguards.					
573 (55.85%)	420 (40.94%)	25 (2.44%)	8 (0.78%)	12	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
12. I feel the service coordinator listens to me and encourages my opinions.					
645 (62.26%)	347 (33.49%)	28 (2.70%)	16 (1.54%)	2	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
13. Our service coordinator helps my family get the services we need in a timely manner.					
620 (60.08%)	323 (31.30%)	69 (6.69%)	20 (1.94%)	5	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
14. In creating our Individualized Family Service Plan (IFSP), I am asked about areas where our family feels things are fine and where we feel we need help.					
623 (60.25%)	392 (37.91%)	14 (1.35%)	5 (0.48%)	5	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
15. We receive all the services listed in our Individualized Family Service Plan (IFSP).					
633 (61.76%)	359 (35.02%)	26 (2.54%)	7 (0.68%)	10	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	

16. All the services I felt necessary were included in the IFSP.					
610 (59.28%)	379 (36.83%)	32 (3.11%)	8 (0.78%)	8	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
17. First Steps service providers were effective and knowledgeable in working with my child's disability.					
642 (62.57%)	346 (33.72%)	30 (2.92%)	8 (0.78%)	12	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
18. I feel the First Steps service providers listen to me and respect my opinions.					
671 (64.96%)	345 (33.40%)	15 (1.45%)	2 (0.19%)	4	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
19. First Steps services give my family the tools to directly improve my child's development.					
631 (61.44%)	369 (35.93%)	21 (2.04%)	6 (0.58%)	8	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
20. The services included in the IFSP were explained so that I understood them.					
622 (60.68%)	394 (38.44%)	7 (0.68%)	2 (0.20%)	6	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
21. I believe the services my child and family receive are appropriate and necessary.					
674 (65.56%)	333 (32.39%)	13 (1.26%)	8 (0.78%)	7	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
22. Individualized Family Service Plan (IFSP) meetings are scheduled at a time and place that are convenient for me and my family.					
683 (66.63%)	324 (31.61%)	16 (1.56%)	2 (0.20%)	9	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
23. Over the past year, First Steps services have helped me and/or my family:					
a. To participate in everyday routines even though we have a child with special needs.					
526 (57.30%)	368 (40.09%)	21 (2.29%)	3 (0.33%)	108	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
b. Feel more confident in my skills as a parent/guardian.					
543 (55.86%)	397 (40.84%)	27 (2.78%)	5 (0.51%)	56	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
c. Understand my child's needs.					
575 (58.20%)	384 (38.87%)	27 (2.73%)	2 (0.20%)	39	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
d. Be more optimistic about my child's future.					
595 (60.59%)	359 (36.56%)	23 (2.34%)	5 (0.51%)	46	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
24. Since being part of First Steps, I can work with professionals.					
506 (55.36%)	378 (41.36%)	27 (2.95%)	3 (0.33%)	97	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
25. Since being part of First Steps, I know how to advocate for what my child needs.					
528 (54.32%)	389 (40.02%)	47 (4.84%)	8 (0.82%)	50	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
26. Our family is better off because of the First Steps program.					
672 (65.69%)	325 (31.77%)	23 (2.25%)	3 (0.29%)	12	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
27. Our child is better off because of the First Steps program.					
731 (71.32%)	278 (27.12%)	13 (1.27%)	3 (0.29%)	7	
Strongly Agree	Agree	Disagree	Strongly Disagree	Does Not Apply	
28. Approximately how often does your family use the help of your service coordinator?					
261 (25.49%)	121 (11.82%)	317 (30.96%)	300 (29.30%)	25 (2.44%)	
Weekly	Bi-Weekly	Monthly	Every six months	Annually	

# *First Steps Family Survey*

## *Summary by SPOE*

*April 2009*

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*Note: Comments are typed as written on the surveys with the exception of the correction of most misspellings. Names and other personally identifiable information of children and families have been redacted.*

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First Steps is a wonderful program. All of the providers have been knowledgeable and helpful. Thank you.

I believe every child is unique. By saying that I mean my child does things differently. My only complaint is just because my daughter does things differently, she's not doing things wrong. At least she gets what she needs done like sitting, crawling and some other things. First Steps doesn't see how she has her own way of doing some things. Just because they are not up to their standards doesn't mean she's not doing a great job. Other than that, they do a good job working with my precious daughter.

First Steps has allowed our daughter to get off on the right track. We are thrilled with her progress and know she will lead a wonderful normal life thanks to all the early intervention First Steps offered. Thank you!

The due process/mediation process is highly disadvantageous and frustrating to parents. We found DESE representatives uncommunicative, unhelpful, and at times, just plain rude. In the end, we have been left to deal with our problem alone.

Thanks to this program and our developmental therapist my child, who has Down's Syndrome, is developmental at her age level. She is able to do almost everything she should be able to do. We just visited the Down's Syndrome Clinic at Children's Mercy Hospital and they were impressed with my child. None of which could be possible without her or First Steps! Thank you.

Great program! Thank you.

I wish First Steps would cover the implant and all that comes with it. It's like discrimination.

Question #28: Calls monthly to check on things.

Don't receive all the time allotted for services. I feel the therapists don't try new things if the old things don't make progress. To help ensure full time allotted therapist should have a log sheet for each family to sign (start and stop times) and log to service coordinator each month. Should make it mandatory if therapist cancels appointment they have to make it up or we sign log saying we cancelled or they did and we are okay if they don't make it up.

First Steps is a great program that helped my wife and I during the development of our child. All of the service providers were great, professional and courteous.

Our worker is wonderful. Shel helps me with anything I ask her and always brings us great information. Thank you.

Our service coordinator meets with us every six months unless I need her sooner than that. She is great as far as meeting the needs of my family in particular my son.

We truly miss our original coordinator. She was wonderful!

I just want to say my child would not be where he is today without the help of First Steps. Our service coordinator and therapists have been crucial in steering us in the right direction in getting the best of care, both medically and therapeutically. I can't say enough to emphasize how everyone in the First Steps program has made us feel like our family means something, that we're not just another number. They have really helped us in beginning the transition process to the school district as well. Our family will always be grateful for giving our son the most promising start!

Our service coordinator is EXCELLENT! She has worked with two of my children. I feel so blessed to have her. She has made the process with First Steps so easy. Thank you.

Although we are interested in the First Steps program overall, our experience with the service provider (occupational therapist) was disappointing. She was friendly - in fact, she spent more time "chatting" with my husband and I than assessing our daughter. She brought the same toys each visit and seemed overly focused on getting our daughter to crawl. Nothing else - but strangely focused on crawling to the point we all sat around for an hour hoping she would. This being said, I contact our coordinator who promptly provided me with another provider to contact.

Our service coordinator is excellent. She always sends information on programs and activities that she thinks would help our son. We would not have known about any of these programs without ongoing support from her.

We have the BEST First Steps lady! We look forward to her visits.

Very good program with committed professionals.

We sometimes struggle getting information from our coordinator. She does not promptly respond to phone call messages or emails to me or our service providers. Despite sending her new insurance information twice, First Steps is still billing our insurance company. She is very polite and helpful in person. We love our service providers!

Question 26: Yes, our family is better off because of the First Steps program. Question 27: Yes, our child is better off because of the First Steps program. Prevention is key! The physical, occupational and speech therapists are all such great professionals. Service coordinator is thorough and gives clear information.

I thank God every day for First Steps. They make a very difficult situation manageable and a blessing. I can't write in words the gratitude I feel with this program and the people I have been fortunate enough to have in this emotional period. I hope this program only grows because there are few things that I believe in in this world today, and First Steps is one of those things. I only hope they will be able to include more developmentally delayed children when our economy is struggling, because even our special children are still our future. Their growth is a reflection of our society's growth. Thank you.

We are just so grateful for our son's team!

My caseworker changes so often I don't get a chance to voice any complaints or compliments. As a result, nothing is done in a timely manner.

She makes a routine call to check in.

First Steps has really helped my family understand my daughter's needs and how to meet them. My daughter is a happier and more confident individual thanks to her therapists. My family is very grateful for everything the therapists and service coordinator have done for us. All the people we have worked with have been very knowledgeable and patient with us through this sometimes difficult process. I cannot thank them all enough. I don't know where we would be without First Steps.

Everyone in the program has been open to anything I've wanted to add or work on with my child. I have never been told no when making my requests. Thanks again for everyone's help.

We feel like we don't really know what's going on with our daughter's therapy and it would be nice to know so we can do what they do at home instead of being different from their therapy. But, she has improved a lot since your services. Thank you very much.

I was very pleased with my therapist that worked with my son. She has been incredible and has been a great asset to our family. I hope you know how passionate they are about their job and the kids they help. I also had another developmental therapist. She was very nice but very unreliable. She "no showed" me more times than I met with her. I wish I would have had a better experience with her, but if I had switched it would have taken my son too long to get familiar with another therapist so I fired her and didn't get another developmental therapist. Thank you.

We must continue to contact our service coordinator to get any response or follow-up. Sometimes we get no response to messages. We are still waiting over a month later to hear what is happening with occupational therapy services for our son and have had no follow-up since the meeting. This has been very frustrating. We GREATLY appreciate the services provided to our family by First Steps. Our son has seen fabulous results with physical therapy and loves both of his providers. His speech therapy is slower to come along and he is on his second provider. Thank you so much for everything. PT,

I, as the grandmother, appreciate you all coming to visit my granddaughter and looking out for her development.

We have a wonderful service coordinator.

Our speech therapist is wonderful!

We've had three different coordinators since services began, but feel each one was excellent.

Thank you so much for this service. It has helped my child and our family tremendously!

Our First Steps coordinator did a wonderful job and she was very easy to work with. However, the First Steps program could be improved, we believe, by providing more help and information to new parents of a child with special needs. For example, when asked what our goals were for our child at eight months, we had no idea what our goals should be. When we asked what they should be, we were told that we had to figure out our own goals. We understand that is the way the program works, but we just feel that First Steps would be more helpful if they would provide parents with more information so that they can set their own goals. Thank you for asking.

It was difficult to get started with First Steps. My son had his tongue clipped at 11 months and we knew before he was okay that he would need help catching up. After his first birthday he was evaluated and did not qualify because he was on target with everything except his speech. I didn't have a concern with anything but his speech. At this visit a speech therapist wasn't there. At two years old our pediatrician referred us to an out-patient speech therapist. While seeing her, he had a hearing test which concluded he had fluid on both ears and possible hearing loss. At this time we had a second First Steps evaluation without a speech therapist (again). I finally got through to someone who made sure a speech therapist came to evaluate. After a third time, he qualified and the speech therapist couldn't understand why it took so long. It took over a year to get our concerns evaluated. He is now doing wonderful with the speech and has come leaps and bounds. But, the process to get him started was long and frustrating.

Question 24: Was able to work with professionals before First Steps. Strange question!

My son has improved in the short time he has been with First Steps. Our speech therapist is absolutely wonderful. My son asks for her when he gets home from preschool. He has become more and more attached to her. He has never felt so comfortable so quickly with anyone. Thank you so much for finding such a wonderful person to help with my son's needs. We truly appreciate every session and will be sad when we no longer will see her on a weekly basis. Thanks again for all your services.

Our coordinator is probably very good, but she seems a little slower in getting things accomplished.

Would like to see more advocacy and be involved in Autism/OT delay in the legislature.

We have a wonderful service coordinator. She always responds promptly to our issues and gives us the help we need.

For the first year of the program, I was unaware that my child even had an IFSP. I never received a copy and thought First Steps simply provided the services. I would also receive forms in the mail with no explanations. Our service coordinator seemed overwhelmed with too many clients. With our new coordinator, things have been much improved. It took a while to get everything set up, but once we got it going, I have been thrilled with her PT and satisfied generally with speech and occupational. However, it was overwhelming to have three different therapists requesting different activities on a weekly basis. At times, they would even have three or four things, or continue to add from week to week, making it virtually impossible for me to consistently do everything they would request. I recently talked to the speech therapist about something we had started, but then quit, to which she said she never intended for me to quit but to add to everything else. At times, this was very frustrating. It would be helpful for everyone to be on the same page, or at least let the child attain one goal before charging on ahead!

Our service coordinator has been very nice and really supportive. The therapists that come out are all friendly and dedicated to helping our son be the best he can be.

We moved here from Virginia a little over a year ago. The services in Missouri are not even comparable~they are so much better than those in Virginia. We are so grateful and happy we have moved if only for the great First Step's services.

I think this is a great program, but I think it would be better if all my child's appointments didn't have to be shared. Because of this, he really only see's his occupational therapist alone once a month because all other times she is with the physical, developmental and VT who are here too. So, he is really only getting OT one time per month.

I wish that First Steps funded music therapy.

We have a wonderful provider and I really enjoy when she comes to work with my daughter.

I am very pleased with the services provided to us by the First Steps program. My daughter is now aged out of the program, but I am very thankful for the help they provided for us. She has made major improvements. Thank you so much for your services.

Question #28: Not at all - maybe in the first meeting then we never heard from her. What exactly is her job anyway? Very disappointing. The service coordinator's position should really be eliminated all together. I coordinated everything.

I was very frustrated with the length of time it took to get a therapist. It took almost two months from the qualification evaluation. When we finally got a therapist, she cancelled three out of the five weeks we had her and did not offer make up sessions. Finally, 10 minutes before she was supposed to be at my house, she called to let me know that her license was expired and she wouldn't be here for 3-5 weeks. I called my service coordinator and was assigned a new therapist and we love her. She is AWESOME! While we love the First Steps program now, we were extremely frustrated in the beginning since it took so long to get a therapist and then were assigned someone who didn't really care about providing good service. I think she was not supervised well and wonder how many other families were given the same disregard for our time and needs as she gave us.

First Steps has been wonderful. The people are terrific. I am so happy to be a part of this program. However, it is very difficult to find out about. At first our Parents As Teachers told us the "Early Ed. Center" through the school doesn't start until age 3 and not to worry until then. Our doctor sent us to Children's Mercy Hospital for evaluation and they gave us a list of private practices (none of which would come to our home because we lived too far away) in Clay county and there was a 12 month waiting list. No one mentioned First Steps. We just happened to have a friend who knew about it. I have since met someone else with the same story who was waiting until 3 for a child who didn't talk because she didn't know of First Steps. Need to get word out to doctors and people who first diagnose problems.

I attempted to advocate for additional services for my child and the service that I wanted are not available. My coordinator did not do much to help or assist me in getting what I wanted for my child. Other states have gotten services I want under IDEA. I asked my coordinator to learn more and contact them. She refused and said that, "the law is the law". I'm disappointed she did not make an effort to research more.

Our current speech therapist has been with us since July, 2008 and she has done an outstanding job working with my girls, as well as providing me with the tools necessary to assist them on a daily basis. We are grateful to the First Steps program for all they have done.

Our OT has been amazing and has really helped our son advance.

Concerning the IFSP, two separate dates were set for the IFSP. Neither one of the dates were followed through with by the area coordinator after the lack of the IFSP being held, my daughter's services were suspended. The developmental therapist was in contact with the coordinator and to date the IFSP has not been completed. Therefore, my daughter's services have not been continued. This has been upsetting and inappropriate, in my opinion, of the service coordinator (I'm unsure how to refer to the area coordinator).

My son needs more services than what is provided. Needs PT and was told none available. Needs OT more than once a week.

Questions #10 and #11: No rights provided or explained.

Question #12: She never calls! She has not followed up!

Question # 14: She hasn't updated our IFSP.

Question #15: NO!

Question #16: At our initial IFSP

I am in the process of filing a child complaint! I have not received an updated IFSP since my child first started First Steps. She received speech and PT and made so much progress that we discontinued the services due to her being "age appropriate". The IFSP that I received after discontinuing the service has no updates in her domains. It states that she cannot sit up! She is running! I let the director know and she brushed it off! This SPOE is a joke! I receive no monthly contacts! My daughter recently has not made progress in her speech and the speech therapist re-evaluated her and found that speech is needed. I spoke to my service coordinator three weeks ago and she was going to "coordinate" the service. I have not heard from her! The providers are amazing, but the First Steps staff are not!

Our son relates very well with all of the ladies as do we. Thank for the great support.

I wish our son could receive speech therapy. Other than that, I am happy with his programs.

Therapists are awesome and very helpful. Thank you very much.

I only had one issue with one service provider. She had appointments with my child and wouldn't show up or reschedule the missed appointments. The last appointment she had, she didn't call, or show up. She called the service coordinator and said there was nothing more she could do in the home with my child. Which was a false statement, there was and still is plenty of goals for my child. She is being seen by another PT and she still has goals to reach and plenty of work to be done. The first PT didn't ask me if I had any concerns or if I thought of anymore she needed to work on. The PT just stopped calling and showing up. She didn't even contact me that she was done. I had to call my child's coordinator to find out what was going on. I don't feel my child's first PT was very professional in the last few months of service. Before that, she was very nice and helpful. I'm not sure of the change in manner. Thanks

I feel like my daughter does not get enough help. We feel it is ridiculous that in order to get a special instructor, one has to come from Chillicothe. I don't feel like that makes your services very convenient.

My service coordinator does a really good job helping me and my daughter with everything we need.

I want to clarify some of my responses. I will say that I and my family are grateful for the First Steps program and what little services we have received thus far. However, our service coordinator has been less than helpful or sympathetic to our family's needs. We had our initial evaluations with a speech therapist and a developmental therapist. After their assessments were complete it was decided that our son would receive speech and occupational therapy twice per month for 60 minutes. The point being that there was no occupational therapist in our initial assessments. After our first meeting with the OT, we were very overwhelmed with the information and techniques she suggested we employ with our son, who was just 17 months old at the onset of occupational therapy. We contacted our coordinator and expressed to her, in writing, that we were literally frightened that we would inflict physical harm on our son if we didn't have more instruction. We requested that he receive extra OT (just in the beginning) and we were told no and that he didn't need it and neither did we. Then we requested a physical therapy assessment (which by the way, was deemed necessary by the pediatric neurologist who diagnosed his autism) because we felt our son did not have appropriate upper body strength. This was noticed not only by his family, but also by his providers. We again, were told no. He didn't need it. This service coordinator remained largely uninvolved in our son's progress, unless of course, she is turning us down for services. We ultimately requested a new coordinator. That request was granted and we have a meeting scheduled with her and all of our son's providers for the 30th of April. It should be noted that when a provider approached her to increase therapy for our son, she berated that provider and ultimately made that provider fear that they would no longer receive referrals from First Steps. I genuinely believe this woman should not be in the position she is in. I have spoken with three other families personally who have had the misfortune of having her as their service coordinator, and all of them had the same experience we did. We are so happy that we switched. We were afraid of switching because we didn't know what to expect, but we figured, it couldn't get any worse. That's the truth. Do with it what you will.

At our six-month review IFSP meeting, our child's (who is hearing impaired) hearing D.T. was absent since she was not notified by our service coordinator in adequate time of the meeting. Our meeting was therefore centered around OT goals. While they overlap in what we're working on, I feel that if all had been present, we may have been able to identify an emerging concern earlier.

Our service provider has been such a blessing to our family. My son looks forward to her weekly visits.

I really appreciate both of our First Steps ladies and I appreciate everything everyone does for us. I don't know what we'd do without First Steps! Thank you!!

Thanks for keeping the funding to First Steps available. This is my third child with the same speech delay.

Our developmental therapist for First Steps, has been THE most important resource I have and I am so grateful for her knowledge and service. I also could not have offered my son the extensive treatment First Steps has enabled me to.

Our service provider excellent to work with.

First Steps has been vital to one of my children! The services have her now walking and beginning to talk. My service coordinator is wonderful, professional and very prompt. My child's four therapists are top notch! We did have one that was not a good fit for our child and Amy immediately helped rectify that issue! Fabulous program. Thank you all

While the services provided have been great ultimately we have received the services we need. Working with the service coordinator has been exhausting and degrading. We've repeatedly been insulted and what should take an hour, instead takes three. They have come into our home with their own agenda and disregard what the therapists (who work with our children weekly) recommend and what we as a family feel our children need.

I am very pleased to have gotten to work with the people in First Steps. This program has been such a blessing to my little one and our family as a whole. Your therapists are knowledgeable, compassionate, and easy to work with. My thanks to all of you who have been so helpful in bringing my special little girl and the world closer together. I hope your program gets the funding it needs to continue and improve its availability to all those who need them.

A comment was made that my doctor's concerns about my child's gross motor skills and language is not a reason to initiate an assessment for my child.

Questions # 6 and 13: Were marked that way because it took First Steps 4 months to find a speech therapist and the coordinator didn't even see that my son needed speech.

It seemed the services my child received were "predetermined" and we were told, "No one receives speech services twice a week." I also felt my child needed oral motor work and the speech therapist didn't feel comfortable doing it. I feel an OT evaluation/services would have been beneficial to my child at that time in helping his development.

I would like to thank you all for everything. You've helped my daughter in so many ways. Though she isn't where she should be, we are a step closer and I am proud of that. So, from the bottom of my heart, thank you. I know my daughter's future will be better because of this program. And, I will never let her forget what all you've done as she gets older and even when she isn't using the program anymore.

I have nothing but good things to say about the impact First Steps has had on our family. Our service coordinator and therapists are truly wonderful. They have helped not only our son, but I have learned so much about how therapy works and why. When we started with First Steps, I was in such a fog and everyone really helped me to know it's going to be okay. Our son is doing so well now too!

We have had a wonderful experience with First Steps! There is just one service provider I feel tries to take advantage of the program and cut the sessions short, but says there is need for more frequent.

Our service coordinator is wonderful and has been very helpful. Our family is so thankful for this program and it has been a big help with our son.

They did their best. I'm not sure it helped but it isn't their fault or training.

Service providers have been excellent. Working with service coordinator has been extremely difficult, exhausting and degrading.

Our family has concerns regarding the team approach to therapy. Our daughter is doing very well so far, but we'd like reassurance that if she needs more than one hour per week of therapy - or therapy from different specialists, she will receive it.

It was hard to find a speech pathologist who was willing to come to us and had experience with a child who had difficulty swallowing. My son has had five different speech therapists. Some had no idea what they were doing. Those that did, didn't want to continue to come to our home. We are very happy with our current therapist. She has worked with my son for ten months. Besides this frustration, overall experience has been great. Our son has medical problems that make doctors unsure what to tell us about his future development. We would have been lost without the encouragement, guidance and optimism of the therapists who have visited our son. Thank you First Steps.

Check monthly visit. First Steps is a wonderful program. We work with skilled and caring professionals.

I think they need more therapists for Andrew county. It took a long time to get my son an occupational therapist and a speech therapist. They definitely need more therapists. First Steps is a wonderful program and has been a great help to me and my son. It is desperately needed!

The First Steps program has been very helpful to us. However, I do have one major complaint/frustration. We started with First Steps so that my son could receive speech therapy. We had no problem (other than the process being a bit slow) setting up speech therapy. When it became clear to us that our son needed to be evaluated for autism, our coordinator basically shut down my requests for more services until we had an official diagnosis. Having a child diagnosed can be a very long process (six months +). We were lucky that our evaluation did not take that long but it still cost us valuable time during which he could have been receiving therapy. Had I known, or been told, to ask for a specific evaluation by an occupational therapist for sensory issues for example, I feel I would have been able to get help for my son sooner. This was extremely frustrating as was the fact that our coordinator gave us information that was no longer correct about where we could go to have our son evaluated and diagnosed. We finally worked through these issues but it would be nice if other families did not have to have the same experience in the future.

I do like the First Steps program and my only complaint is that I have to drive one hour and fifteen minutes (each way) to my daughter's speech therapy appointments - twice a week since a speech therapist is not available in our area.

The only problem that I have had with First Steps is the difficulty in receiving physical and occupational therapy weekly. When a child has individual needs specific to occupational and physical therapy, the family should not be encouraged to choose only one service. We were encouraged to choose either physical or occupational therapy, but we had to push to get our daughter both services weekly. I understand that this "primary therapist" is a way to cut costs, but it does a disservice to the child and family.

We have had good results with First Steps. I continued to complain about my son's ankles to his doctor without results. When I complained to First Steps, it wasn't long until he was evaluated and then received his braces. He hardly, if ever, falls now and his gait has improved greatly. The only problem we really have now is getting the Parent as Teachers to come out. It's been over six months since we have seen her. I call the school and, according to what the school says, she is at school all the time helping teachers. I am worried about what will happen when he turns three in June. We will no longer have First Steps at that time. Thank you greatly for our First Steps program.

The first coordinator we were assigned decided, on her own, that my child's medical condition (Hydracephalus) did not qualify for services because she deemed it "stable". The condition became progressively worse over the next fifteen months when we were evaluated for First Steps services a second time. At that time we were told that her medical condition was qualified the entire time. We feel that our child missed out on quite a bit of therapy she could have used. When we finally got our services started, we were assigned an occupational therapist who apparently doesn't know how to address our daughter's oral motor issues. With barely four months left that we will qualify for services, it is difficult to decide if we should try a second occupational therapist or just wait. Overall, the services she has received have had an incredible impact on our daughter and our home life.

Early on we were very overwhelmed with our daughter's disabilities. However, our service coordinator and service providers are excellent and give hope. We would not be in the positions we are today without them. Thank you!

My service provider doesn't respect enough to call when she can't make it. I have waited on her all day long on three occasions and she has been a no show. No call. So she doesn't stick to the plan of seeing us every other week. Sometimes it's every week. Sometimes it's every three to four weeks to make up her missed time.

Our First Steps coordinator was fantastic. We recently switched and she seems knowledgeable as well. Thank her for a positive First Steps experience. The only thing I don't understand is why First Steps does not cover batteries, cords and CI pants for the external components.

First Steps seems like a good program. Our provider was knowledgeable and efficient. However, our child didn't have serious needs and it felt that because we were receiving service our provider had to find things she should work on. It was discouraging and since we've cut back significantly on services she has developed well and I have felt more confident as a parent.

The coordinator and I met once! The speech pathologist sees my son once a week. The service coordinator, to me, seemed like she did not have a lot of time for me, my son or a way to help my family.

I really appreciate all the help we have received from First Steps. My daughter has greatly benefited from the services. Your program is a wonderful blessing for families and children in need. Thank you so much.

First Steps is the best thing that could of ever happened to our family. He wouldn't be where he is today without this wonderful program! Thanks.

Thanks for all services that I received for interpreter English-Spanish. She is wonderful. My therapists are excellent and very professional. We are an excellent team.

Changed therapists to take care of this problem. Very happy now. (Q17)

The time it took to set up my child's program was unacceptable. I contacted them initially in January, he (my son) did not start seeing therapists until late March. I would be contacted by different individuals and have to relay my story/situation over and over and over. Very poor communication between people at First Steps and the DCO therapists. Therapists went to the wrong day care center (poor communication), one therapist gave me her son's cell phone number instead of her own to contact her. There were no therapists at the initial meeting to go over their evaluation and set up his program. Only the service coordinator and I attended. I know she was trying to just make progress at this point because it had already been thirty minutes long, but this was a mistake. There was also a huge delay because I lived in a different zone than where the therapy was to happen; HUGE ordeal.

I was unaware First Steps had it's own evaluation until after Children's Mercy had completed its evaluation. I highly recommend pediatricians inform parents of no cost to us. \$700 fee to Children's Mercy in order to make the best decision!

Great program and a wonderful staff.

Our coordinator is the BEST part of the First Steps process for us. She has truly shown an interest in our family beyond just our daughter and we are a better family unit with her help. She cares and that makes all the difference. She does way more than just doing the requirements of her job, and we appreciate her involvement in our case very much! I would also like to add that it would be my preference to have the option of either in-home or on-site therapies since some kids, like mine, seem to respond better in a new and exciting place, especially for physical therapy.

My oldest son qualified for speech at eighteen months and then my other son did not qualify initially even though he had more delay.

I would be nice if parents can rate/score the providers. It will help families to have the better match. We went through so many professionals and none of them were able to help us. It takes a long time to add new providers (sometimes three months). I'd like to see improvement and simplification of the process. First Steps hiring process is a very long process. Some of the implementors took 3-5 weeks to be hired.

Thank you! Because of First Steps my 28 week boys are performing now at their chronological age!

We love our team. Our provider is wonderful. My daughter and I enjoy our time with her each week!

The service coordinator worked to find service providers to accommodate our work schedule.

We are very impressed by all of the positive improvements in the First Steps program. We have the best therapist we have had yet!

Only complaint is that things take forever to get done. Otherwise, it is a really good program.

Thank you very much.

We haven't been in this program long enough to give a lot of feedback. Our main complaint is that our therapist visited with our daughter one three times. She was finally starting to "warm up" to her and she quit on us. I never heard directly from the therapist again. Our service coordinator called to say she needed to find us a new therapist. Essentially, one that has a lighter caseload. This is specifically what we wanted to avoid and I made that clear to our therapist before we ever started the process. We want one consistent therapist to come into our home and work with our daughter. If we continue to get "moved around" we will consider cancelling services with First Steps.

I think I need help every week. I think someone needs to get us a physical therapist like they said they were going to. I do think First Steps has helped us a lot. I hope they continue to help us. Thanks for all of your help.

The IFSP paperwork is extremely confusing. Can't figure out how to make sense out of it. Lots of money wasted on the paperwork mailed every month. I pay nothing but still receive a statement indicating a zero balance with an envelope to mail my payment back. Waste of money waste of trees. Haven't you heard of "going green"?

Question #24: I assume you mean working with varying professionals for the ultimate best care of our daughter (ie: doctors, therapists, child care workers, person who are experts in their field and can provide relevant information, etc.) I found this statement very vague. We love our coordinator, Carey Vollmer. She is always knowledgeable about available options and alternatives. We have valued her advise on a range of topics including determining alternative possible treatments for medical conditions, day care placement, and what therapeutic options may exist for emerging concerns that do not fall directly under the umbrella of our other therapists.

Our service coordinator has been wonderful to work with. We feel she truly cares about our child and his progress. The therapists have also been great ~ they have all developed a relationship with our child that makes him want to work with them. Thank you.

Everyone has been great in every way. Coming to our home so we don't have to go to St. Joseph every week is so helpful. My son's speech has greatly improved and we are so grateful. Thank you from the bottom of our hearts.

I wish services were available to my child other than just one day a week. Sometimes things come up and he can't have services done on that day and she doesn't offer to come on another day just the following week.

We are thankful to have this program. It is a great support.

I would like to say thank you so much! Everyone we have met in the First Steps program has been extremely kind and caring. We absolutely love our son's speech therapist. She is truly a blessing to him and our family. We will never forget all the help and the kindness he has received to start his prominent future.

Our service coordinator was fantastic! She was empathetic and very prompt. Great follow-up and excellent program. Love this program!

Fabulous and very professional. Thank you.

Our physical and occupational therapists and Susan Luse have been outstanding with their help and guidance with our child and family. Thank you so very much.

The personality of the therapist is about as valuable as his degree. She is one of the people working with us and she is wonderful. We can tell that she loves our child, and feels comfortable in our home, which helps us to feel comfortable to have her in our home. She's firm with the children, but does not get upset or uptight with a child that does not cooperate. At the same time, she is also very flexible, putting the child's wishes ahead of her own. She is careful with her language, not to use offensive words in front of our children. This is very important to us and we appreciate her efforts. I was very sorry when she was no longer allowed to bring toys along. The children really miss it too. I wonder if this rule could be changed? The children cooperate so much better when she brings something new along. I realize that the person who made the rule had a good reason for it, but I'm not sure it was the best for us on the receiving end. I would be happy to see this changed again back to like it was.

I feel fortunate to have her as our service coordinator. She, along with the tremendous support we receive from Gertie Matavalli, Kim Westhoffand Lori Kammerich, has made our journey with our son's development a remarkable one. I am so grateful to each of these women for their compassion and commitment to success for him.

Our situation is a little different. That is why some of the questions don't apply. Our son was a foster child and he had already begun services the month before he came to us. I love his service providers. He receives occupational, SI's, and speech therapy. He is "consult only" on physical therapy. We have been involved in the program for five-and-a-half months and are very pleased with the information we have received as well as the therapy he is receiving.

We have moved.

I'm very thankful for First Steps.

I feel very strongly about the help my child has received. The home services were great, but the center based structure and socialization is what really made a difference in his progress. I hope that Missouri First Steps continues to support center-based programs. My son couldn't be as successful today if it were not for his experience.

Services, for our daughter, started when she was fourteen days old. Our child is being set up for a successful life because of this program. Words on paper cannot express my gratitude towards this invaluable program.

First Steps has been wonderful to our child and family. First Steps is highly recommended by us. You've been a wonderful service to us.

I am so glad that my family became involved with First Steps. Since they have started coming to our home and working with us, we feel more confident in our child's potential and in our ability to reach her full potential. The First Steps program has made us feel like we are not in this alone. We have seen improvement in her motor skills and communication abilities. We are very satisfied.

With the help of the First Steps program, our daughter no longer needs physical therapy and has resolved many of her issues from being premature. We are grateful to the program for their great assistance.

Have not been in the program long enough to answer questions 23a, 23b, 23c, 23d and 25. I am very satisfied with the program and hope to continue services until my child no longer needs them. Thank you for your help.

Great work! Keep it up!

Our experience with First Steps has been wonderful. Our service coordinator is great! The speech therapist that comes to our house is so good with our son. I am very thankful for these services!

First Steps has given our family hope. Doctors have been very negative, and his therapists are encouraging. We have been given tools to help our child succeed and he is improving every day.

I am sad to hear about some of the changes to the program. I hope that every family can have the incredible experience our family has had. Thank you.

Our speech therapist is excellent. She comes with motivation and knowledge. She works geared to my child. She has definitely been a big reason why my child is doing so well today.

We had a fantastic experience with everyone associated with the First Steps program. It was a lifeline for our family during a frustrating time and I will be forever grateful to the individuals we met through the program.

June 11, 2009

I have to take a moment to acknowledge how incredible the First Steps Program has been for my family. Eighteen months ago we didn't know if we were dealing with Autism or some other developmental delay with our then 18-month-old son. These past eighteen months have been life changing for him.

Our service coordinator has been an advocate for my child. She was sure that his evaluation was thorough and that all of my concerns were addressed and questions were answered. She structured a team of service professionals that not only worked with our son, and educated us as to how we too can help him, but everyone empowered me to get additional help for my son when dealing with medical professionals. When I walked into each doctors office (and there have been many) I was empowered to be my son's advocate because of what First Steps has taught me. You can't imagine what a blessing that is.

She has been instrumental in my son's progress and we thank God for her. She has been wonderful to our family, and in a world where so few people care so little for others, you can see that she is unique. You can tell when she is putting something together for our son that she has his best interests at heart.

This program is very effective and like I said, "life changing", but it takes dedicated professionals to make a program work, and she has those those qualities (and many more).

The First Steps program is wonderful-Don't change a thing!

One of the main reasons we signed up for First Steps is for a speech therapist. We have yet to get one!

Our services are critical to our child's development. Now that we know his needs and delay in such detail, it is frustrating that he was initially denied an evaluation. He was close to not qualifying yet he has a considerable delay. More First Steps help is needed.

I have greatly appreciated the services of our coordinator and therapists through First Steps. They have helped my son to excel greatly! Thank you.

Without the weekly services we receive from all providers we would not be where we are at. We need everyone weekly to accomplish what has been accomplished.

I did feel it was very difficult to qualify for First Steps.

I am an speech/language pathologist and was a prior First Steps provider; therefore, I was familiar with the program and knew my therapists personally.

Some services through First Steps are not readily available because of the availability of therapists, such as nutrition. In our county there is a wait list for the nutritionist and then they don't even service all of the county. Our coordinator has been so helpful. She really goes the extra mile to make sure that we have everything we need. We appreciate her and the therapists that we have. They have all made a difference in our daughter's life.

Question 28: Approximately how often does your family use the help of your service coordinator? Well, we have therapy one time a week, but we don't use her therapy so I'm unsure.

One of our service providers was not as effective in meeting our goals as I would have liked. We switched after several months and are now very happy with the progress our child is making with the new provider. Parents need to be enabled and encouraged to change providers if there is any uncertainty with the situation.

I would like to see 1st Steps assist children with mild disabilities be more integrated into the regular society. (such as: helping families with financial assistance not just for special needs programs but also typical programs: like karate, basketball, football, music instruments, etc.) It is important to integrate special needs children and adults into the typical society.

We are very appreciative of the services from First Steps. It's very important for our son to get the therapies he needs.

Once finally learning of First Steps, the experience has been wonderful! Our coordinator is the best.

Eye sight services, after requested, were not evaluated for. I had to contact a separate center to get services. Also would like to see sign language services added for non-verbal individuals.

I am very pleased with the services I receive from First Steps. However, I do believe there are areas you could improve on. My child should have been getting occupational and speech therapy sooner but no one told me we had to ask for it. I assumed the physical therapist that saw him/her would notice and recommend more services. I hope that First Steps does not try to have one therapist doing the job of all the other therapists. In the future, I hope they continue to give children services of all therapy necessary by the therapist who specialize in that area (speech, OT, PT). Thank you.

We are very thankful for the First Steps program. Our son's speech therapist has been a great help in getting him to eat. The only thing that I feel could be improved is shortening the time it takes to get from your doctor's referral to the actual first treatment.

Questions 28: Approximately how often does your family use the help of your service coordinator? He is no longer in First Steps, but he did use.

Our coordinator is not organized and it takes her awhile to get back with you, until I complained to her boss. Sometimes the therapist took forever to get her. I already knew how to participate in everyday routines even though we have a child with special needs; feel more confident in my skills as a parent/guardian; understand my child's needs; be more optimistic about my child's future. I already knew how to work with professionals. I already knew how to advocate. My residential case manager helps me more than my First Steps coordinator because she knows what she is doing. The Special Learning Center is awesome.

I wished I could get more time with the speech therapist.

Great program!

The doctors and nurses of Children's NICU introduced us to First Steps and not too many days after coming home from the hospital we received a phone call and it was explained in a professional matter. We are very blessed to have had and still have these services for our son.

The PT seems to do more for my child than the OT therapist does. Otherwise they all would be strongly agree.

We have been blessed by the First Step program workers - they have done a wonderful job on our twins - they are angels to us. It's a wonderful program and helps when you have good people too!!!

Q22: The time the speech therapist comes each week is not convenient but the only open time.

We enjoyed everything about the program. My child is a totally different child!

My son has some great teachers and treat him wonderfully.

The First Steps Program has been a god send. Every person that has worked with us and our child has been caring, concerned, compassionate and professional in fulfilling our needs. Thank you so much!

The person we work with is wonderful! It's because of her that my daughter started crawling and improving. She comes with us to our Dr. Appt's out of town. We love this program and your staff.

My husband and I am so incredibly thankful for First Steps program. We have learned so much from our First Steps providers. Thank you!!

First Steps has been a blessing for our family. We are so thankful for the opportunity to receive early intervention services for our daughter. The evaluators, service coordinators and service providers have all been great. We pray that First Steps continues to receive the funding and support needed to continue to provide early intervention services. Thank you.

My child was told he needed OT and PT and that we would receive these services but never have.

I really appreciate the convenience for holding meetings and therapy sessions at our home. Thank you! Everyone we have come in contact with has been wonderful!

My son's therapists are great. They have already made a difference and have helped to address all of my concerns appropriately. My son looks forward to them coming.

This is a fabulous program! I wish it were more well-publicized. Thanks!

Need more therapists in Carter/Reynolds!

When we were getting physical therapy for our daughter the Provider failed to make appt once a month! Also our Service Coordinator is a very good service coordinator and we want to thank her very much.

My child has only received services for a few weeks, but we are seeing progress already!

Fabulous program so glad it exists!

Everyone that we worked with was great!

The First Steps program helped my son to learn to try new things and gave him the confidence to begin learning new things on his own. He can now explore and test his physical abilities and limits with no hesitation. I believe the First Steps and the physical and occupational therapists were very beneficial to my son's growth and development.

First Speech Therapist was great with my son but halfway through was not very patient with him.

First Steps has been a godsend to us! Our coordinator helped us get everything organized and planned out for our child's needs. Our child's therapist has been such a great teacher to our daughter. She is an outstanding teacher who is helping our daughter overcome her speech disability. Thanks for having such a wonderful program.

We have the best team working with our son and I cannot say enough wonderful things about them. They have helped us in so many ways. Our son has made amazing progress! I love the First Steps program.

First Steps is an amazing program. Although a bit difficult to understand when first introduced to the program, now that we know the "rules" and interpretations, it is easier to navigate. The service providers and coordinator have been wonderful and we will miss them when we transition to early childhood. Thanks to First Steps, my child is developing wonderfully!

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Questions #24 and #25: My spouse and I are professionals who have long advocated for the needs of our child and others. These skills are not a direct result of our First Steps involvement. We are able to effectively advocate for our child's needs and share specific concerns with First Steps staff.

Once services are started it's easy to use them. It just seems like a long process to get started.

First Steps has been a godsend for our family and our daughter. She was the first child on either side of the family born with a disability. Since starting the First Steps program, she has progressed so much that our friends and family are simply amazed and grateful. All of her therapists have impressed us so much. They have gone above and beyond our expectations. They taught us to expect more from her and so far, we've gotten more than we've expected. I can't thank First Steps enough for the absolutely fabulous start they've given our family and our baby girl. I am so thankful that we live in a state that provides such an amazing resource for it's families.

A wonderful program for early intervention. I wish that there didn't have to be such a big gap in learning/development to get services.

Our service coordinator has been excellent. She is very organized, listens to our concerns and overall very nice.

Wonderful. Thank you so much for all of your help. We would be so far behind without these services.

As first time parents raising a child with a disability, we are grateful to have First Step's services provided to our family. Our child is a gift and the coordinator is nice but most of my accolades go to the physical therapist who has helped us understand things we didn't know and was always concerned outside of the work relationship, encouraging us as parents. I appreciate that the workers sent to our home are here to do a job and help families reach goals. Even when I had a developmental therapist who would frequently miss appointments, I was able to discontinue her services and was satisfied. She also seemed as if she was unexperienced. I felt no connection as if she were insincere.

Question #24: Being in a home environment can be a professional atmosphere. We have jobs so we are always in a professional environment and have experience. First Steps does help our family to be optimistic about his future. We also believe in God and realize that we are very fortunate because, overall, he is a healthy, happy child.

I have really enjoyed my son in this program. If I've ever had any concerns they were addressed immediately. I will miss First Steps when my son can no longer receive it.

The only difficulty we had was finding out about First Steps. I recall one of the doctors writing a phone number on a piece of paper. I think it would be helpful if hospital staff were given materials or brochures to give to parents after a disability is discovered after birth. It is stressful enough having a baby, then getting a difficult diagnosis. A social worker never came to talk to us. That may have been the "missing link"! Other than that, we love First Steps.

She is my son's first step therapist. I couldn't ask for a better person, I consider her a good friend. She has done amazing things for my son and my self-esteem. I consider her the reason that I am more confident in my parenting skills. I can't praise her enough.

Ever since she has started with First Steps she is learning and saying new words every week.

Our PT, is awesome. She is so good, and my child has really excelled in his physical abilities. Also, we are very thankful that First Steps provided the funds for his orthotics. It is a wonderful program

It often takes too long to get the IFSP scheduled or make changes to current services. This caused a delay in getting services we needed.

Q13 - Not easy to find all services in our area

I am glad our child was able to receive the individual therapies from PT, OT and speech instead of the one therapist I'm hearing about in parent support groups. We're lucky we didn't have to give up time on one development area to focus on another. She is doing very well in preschool. We couldn't have learned everything we needed in one hour a week.

We are so blessed to have First Steps. First Steps is awesome. Our little boy is getting the education he needs to help him progress as he needs to. God bless all of our people that come and work with him. He has improved so much in just six to eight months. Thank you.

Our service coordinator is great. She follows through, contacts regularly, listens, helps me figure out the next steps to take and our options. I wish the be-annual meetings could be scheduled such that all or at least most of the providers could be there. That connection is really important to the whole picture and process of the child. I also have advocated my Parents as Teachers coordinator's involvement. So much is interconnected and needs to be worked that way. As for developing the IFSP, I wish I got more input on what to include. I don't know what my goals should be for our daughter and my providers know so much. Their input, rather than letting me come up with the goals, would be helpful. The providers are all amazing. Thanks to everyone.

We found our service providers on our own and travel 22 miles round trip to get the services we need. The providers are very good. We wrote and explained the services needed to the coordinator. We have advocated for our child and educated ourselves. In fourteen months, we've had 3 different service coordinators and didn't have one for six months. Each time we were the ones educating the service coordinators on First Steps practices, and what we needed for our child. We do now have a competent service coordinator, but she is not the one for our area. We still provide the service codes and locate our own providers, but at least things get processed as needed.

Related to Question #19: Although not provided

Provider was continuously late after scheduling appointments.

We couldn't be more impressed with our service coordinator. She is wonderful, efficient helpful, and unbelievably good at having things done in a timely and accurate manner.

Processing of things like paperwork to get orthotics should be put through quicker than 2 weeks. It will then take over a month to finally get them.

Everyone involved with First Steps seems very friendly and knowledgeable. I love being involved in this program and feel it is beneficial to my son.

It would have been better if we did not change coordinator so often (at 4 different ones)

Our service coordinator and therapists are awesome!

The program is a very appreciated and great success. I wish that everyone could have such a wonderful program to their needs.

Information not readily available/communicated via privately owned daycare centers. Consistent with communications and addressing child's need aggressively. Smooth transition into program and to local school program.

Regarding Question #4: If we had not participated in the Parent's As Teachers program we would have never learned fo First Steps. My concern's with my child's needs were regarded as normal development delays by medical professionals even though I know he needs extra assistance.

Regarding Question #6: It was extremely difficult to get approved for the program - primarily because of Missouri State guidelines. It was very frustrating to hear evaluators say, "Yes, your child needs our services, but under current guidelines, does not qualify". I would love to see First Steps provide services for a nominal fee for those that "don't qualify" but still needs services per the evaluators opinion. (We had looked elsewhere for services, and even though we had insurance ssessions were being quoted about the \$300 level per weekly session) and this was out of pocket expenses. After we managed to qualify, services has been great and we truly appreciate those who have worked with us. Thanks.

Speech therapy was not very effective but physical and occupational therapy were great.

Our child's therapist is excellent. She goes out of her way to make sure that our child's needs are met.

Our service coordinator is somewhat delayed in communicating back with me about plans to be made and my therapist have some troubles with him as well.

St. Louis Children's Hospital was instrumental in seeing that our son got set up with First Steps - they and their discharge coordinator were amazing. We are so thankful for this service and for our service provider is amazing with our son and we look forward to her visits. Our service coordinator, Wendy Allen, has been wonderful and checks on us regularly. Our son was a preemie and First Steps has taught us a lot about his development and helped us to be better, more confident and involved parents.

We are so thankful for all the people we work with in the First Steps program. Our coordinator is excellent. Our physical therapist is amazing.

We're grateful for the First Steps program. Our therapists for physical therapy have been wonderful.

All the therapists are doing a great job with my grandson. They are always willing to explain things to me or help me with a problem I might be having. It takes a lot of time and questions on how to deal with a child with special needs. Most people these days don't want to take the time to help someone in need of help. I want to thank all the people that help me and my grandson get through these tough times.

We changed service coordinators when my son was two months old. Our first service coordinator was difficult to work with and I did not feel that she respected our opinion. We had a completely different experience with our second coordinator.

It has been instrumental in the growth of our son.

Our service providers and coordinator have been incredible. Having them be a part of our son's life has given us new hope and sky-high expectations!

Although I feel the First Steps program has definitely enriched our lives through your service providers I am definitely DISAPPOINTED in our service coordinator. She doesn't seem to care about our needs as I feel that she should and is always late and has only contacted once to see if she scheduled a meeting.

I couldn't ask for better people for help with my child and my family. These people give me hope about my child's future and prove to my family that my child can learn and function as normally as any other child.

It was easy for us to learn about First Steps because the hospital provided us the information. Our preemie has been lucky and is developing wonderfully and has not needed services. Had we needed them, I was thankful that First Steps and our coordinator would have been able to help us.

Need to find a way to make more Missouri children eligible for First Steps, because early intervention is crucial to the well being of children and the health of our nation.

Add nutrition service options. When we were receiving services from a nutritionist, her agency was the only provider and I wasn't pleased with her services. We needed suggestions for weight gain, and her recommendations seemed unhealthy. Not what we were looking for! The other providers (OT and PT) are wonderful!

When you are dealing with an infant, evaluations should be implemented every four to six months until regular visits are deemed necessary. This would include but not be limited to speech, physical and occupational therapy evaluations. These could aid parents in doing what they can until regular visits commence.

The process of getting additional sessions approved is very difficult and unnecessary. If a child needs help it should be a simple process, but ours took four emails of much persisting on my parent part to get one session approved. This turned me off to First Steps.

With your help my son has made huge strides towards living a "normal" life. Thank you.

Our coordinator has made first steps an awesome experience! She always listens to what our family needs. We love her!

Our service coordinator was great and our providers are were fantastic! Thank you.

Questions 24 and 25: These questions are not always valid. The statement could not be true for a family but that does not necessarily mean that the program doesn't meet said needs, for instance, those are not concerns or areas in which our family needed help with, but it also didn't hurt. I recommend rephrasing the statements. The program is wonderful and we greatly appreciate it. Thank you. We had a difficult time trying to find the program. Not only was it not advertised in places or at times that we were aware of, but agencies within the state didn't even know what it was or how to obtain contact information.

Question #17: Just his therapists only. Question #19: My son's therapists are wonderful, but with everything else, I'm not happy. Question #25: Did it on my own! Our coordinator was horrible Question #27: Because of his therapists, our family is better off because of the First Steps program. Question 27: Our child is better off because of the First Steps program. But our therapists through First Steps were the only good thing about it. To Whom It May Concern: Our First Step coordinator was horrible. She lied to me many times. There were many other things we could have done through First Address. When I asked these other programs, I was lied to. My son's OT, DT and speech therapists are wonderful. I am getting more help from Special School District then I did with First Steps.

First Steps has been a true blessing to our family. Our service coordinator has been so wonderful throughout our time in the program.

First Steps has not only helped my daughter with her needs, they have helped our whole family tremendously. Without the help of First Steps, we would have not known of the service available to help our daughter. We love you!

We had difficulty getting our child evaluated for speech therapy before eighteen months, so we found a speech therapist on our own. The rest of the services our child has received have been great. It did take a while to find therapist who would come to our house, so it would have been nice to have other options for therapy during our wait.

I filled this out about our current therapist. When we first started the program, we had a different therapist. We didn't really click with her and we requested a change. Since switching, we couldn't be happier.

Question #24: "Since being part of First Steps, I can work with professionals." I was able to do this WITHOUT First Steps! The way you listed this has me feeling uncomfortable and was NOT at all respectful!

Our coordinator is so amazing. Her help has been critical to my child's services and she has even been helpful in working with me to position ourselves for services after the boys turn three. I don't know what I would have done without First Steps. We owe you all a lot of thanks.

I can't say enough in praise for my providers. They have been very very helpful and professional. I have seen a great change in Jade. She has done a 180. They have given me some good advice and it has proved to be very beneficial. They and the First Steps program are a blessing.

Missouri is extremely blessed to have this program. Thank you for making it so much easier to get the early childhood intervention for our little one. Our PT is amazing! Thanks

Though our son is doing well it gives us a little peace of mind to have First Steps come by just to make sure that we're on track. Thanks.

I want to know if my child is being seen like she's supposed to.

I am so glad our child and family has joined First Steps. They are a wonderful and helpful resource for our special needs baby and our family. They are very generous and kind and I would and will be sad when the program ends at three years of age. I worry if my baby will receive the kind of support then (at 3) that she does now.

The providers are a huge part of my daughter's success. They are great! Thanks for what they do!

First Steps made a large difference in not only my son's life but our's also. We were scared and lost and then First Steps came to us. We have met wonderful people who care and encourage us. Thank you. She has gone above and beyond to help us. Thanks from the bottom of our hearts.

We love our First Steps provider.

First Steps has been the best thing we could have done for our daughter's follow-up care. The services we receive are absolutely wonderful and have made such a hugely positive impact for my daughter and for the rest of the family. This is a fantastic service!

First Steps is a great program. The only problem that we have had with the program is it took forever to get a physical therapist. Other than that, it's been great.

First Steps needs to watch who they have as physical therapists. Especially those that make home visits.

I think it's a wonderful program.

We have had difficulty finding people who are willing to do evening appointments - everyone is booked. Both occupational therapists that we had just decided on their own to stop. Our physical therapist and speech therapist have been excellent. I am not happy that our service coordinator will be changing. She is familiar with my child and everything that we have been through so far.

We have a great therapist.

First Steps has been a life saver. My child has improved a great deal and I'm excited to see all of my child's improvements. Thanks to all.

First Steps has been instrumental in getting my son where he needs to be developmentally. I value all my son's therapists. Each gives great help to me and my son. Each has suggestions for things for my husband and I to work on. I benefit from seeing each individual therapist work with my son. I watch what they do with my son and that is why I can continue these services on the days the therapists are not at my home. I have heard talk of the program changing in regards to only one therapist going into the home weekly and explaining what the other therapists on the team want the parent to work on. This is ridiculous. How would a PT be able to effectively tell and show a parent what to work on in speech. This is not the PT aarea of expertise and it should not be part of the PT job. Parents need to see first hand what each therapist is doing and what the therapist wants the parent to work on before the next visit. If this change is implemented it would be a great disservice to the parent, therapists, and especially the child.

I have the best physical and occupational therapists. They have helped me and my daughter out so much! I am very thankful for all their services.

I can't begin to thank First Steps for helping my daughter. When we started the program, she was seven months behind on her speech. Her therapist taught us sign language so we could communicate better. Over the past two years she has just soared and made remarkable progress. At age two-and-a-half, she was tested and is about her age bracket. She is actually one year ahead of where she needs to be. This is an amazing program with amazing speech therapists! I am very grateful to have the opportunity to work with them. Thank you so much!

Although in theory I think his is a good program, I felt the testing was not accurate (nor did the pediatrician) and grossly under estimated development. I felt this was done to allow services and in particular, money to be paid to the program!

Before our daughter came home from the hospital, she had been diagnosed with a hearing impairment. We were stunned and saddened by the diagnosis, but were very fortunate that Missouri has a program like First Steps to help us and our daughter get the assistance she needs. Without First Steps, we would have been unable to find or afford the help our daughter needs in a timely manner. However, there have been times that we felt that the program didn't take into account the changing needs of our daughter as she grows. For example, only so many ear molds are covered by the program per year. When children are very young, they need more ear molds made to keep up with their growth. As they get older, they need far fewer. The program only covers a set number of ear molds per year which doesn't take into consideration the change in the number of ear molds needed as a child gets older. Since the State of Missouri requires newborn hearing screenings, we're sure that this issue will come up more often. Another problem we had early on, was that we had to wait for the first IFSP meeting before our daughter was able to receive her hearing aids. We understood the need to get the paperwork in order before receiving services, and we had done that well before the first meeting. With hearing impaired children, the earlier they can receive hearing aids, the better their chances are for normal hearing and speech, especially for infants while their brains are making the neural connections to the sensory organs. The fact that Missouri requires the screenings implies that the State understands on some level that time is of the essence. A few weeks one way or the other may not seem to make much of a difference, but developmentally, it is a world of difference to an infant. We could've paid to have the work done earlier, but with all of our other medical expenses at the time, we couldn't afford to pay for hearing aids. Overall, once we started receiving services, we have been very pleased with the program, our service coordinator, and service provider. We are impressed by the follow-up of those who work with the program. Without First Steps, we think that many children in our daughter's situation might "fall through the cracks." For the most part, our daughter is receiving the services she needs when she needs them, which we most likely could not provide without First Steps. Finding out about our daughter's disability was difficult, but finding out that assistance was available and relatively simple to apply for made all the difference for our daughter and our family. She is doing well, thanks to First Steps.

I feel very thankful and grateful to have used the services offered through First Steps. My child's therapists and service coordinator were excellent. Because of early intervention my child continues to excel. I would just like to say thank you for all of your help in achieving this.

The therapists in our area are excellent and we are strong believers that therapy has helped our son tremendously.

Question #16: All the services I felt necessary were included in the IFSP, but the program/service coordinator was reluctant. Question #17: First Steps service providers were effective and knowledgeable in working with my child's disability except for the physical therapist. Question #18: I feel the First Steps service providers listen to me and respect my opinions except for the physical therapist. Question #23c: Overall, we have been very happy with First Steps and the service providers. We have had effective, knowledgeable, caring and helpful professionals work with our child and family. I would like to note on #18 and 23b that we had the unfortunate experiences of working with a PT who was ineffective for our family and unfortunately, probably other families. I felt that she hurt my confidence as a parent to a child with special needs and continually disrespected me and my family. She was almost consistently late without apology or respect for my time. She was unable to create a helpful relationship with my child. She acted unprofessionally in the following ways (to name a few): Told me that if she spent one weekend with my child who is/was unable to do consecutive rolling) she would have her rolling (as opposed to my efforts). Told me I should try leaving my child in her high chair for a few hours with food in front of her to get her to feed herself (which she currently doesn't have the skills to do) Acted childish when we tried to address conflicts and regularly smacked her gum (this is minor in comparison, but unprofessional) Thanks to the current providers we are very happy with the team and are hopeful for our child's development and future. We appreciate the services and help that First Steps provides.

The First Steps program is great. But, there is one thing you guys need to work on like getting the paperwork done a little faster. I have three kids in First Steps and sometimes it will take three months or more to get things because they are waiting on paperwork so they can do it.

Our service provider was very professional and very helpful. She was a very pleasant young lady.

Our therapists are all wonderful. We are very happy with all the services.

We feel that First Steps should provide some assistance with Aquatic and Equine therapy.

Question #24: I've always could work with professionals. I don't understand the question. Every therapist we work with is on time, professional, friendly and helpful. I feel like I have "The A Team".

We loved First Steps!

Our family is so happy to have such a knowledgeable speech therapist. She is very good with our son.

I'm sure the fact that I answered all questions, "Strongly Agree", can appear generic. But, please know it is truly how I feel. This program has been a godsend to my family. I was so nervous and anxious that my son might need "special" help but my whole team made everything so easy. They never made me feel like my son had "problems". My son has so flourished under they're care...it is truly miraculous! The fact that he looks at me and comes running into my arms and says, "I love you", is just a miracle. I have a connection with him now that I never had before. I also loved the fact that I got to pick his individual therapists. It was great to find people that were right for us. I think that people underestimate the power the right connection can make! I wouldn't change a thing...I sing your praises to everyone that will listen. Thank you for being part of our MIRACLE!

My child has greatly improved in the things she was weak in. I highly appreciate the help they provide and how much they care about her and her needs.

My provider is great! Wish my calls were returned the same day by my service coordinator.

First Steps early intervention has changed my child's life. Our service coordinator is thorough, timely and professional

I thank you very much. I have seen a big change in my son. It's been hard on me since September 2006. I lost my first son to SIDS when he was two months old. My son now has been very challenging for me after my first experience. But, since I can't change what happened, I can get the best care and I found that with you. Thank you again!

It was extremely difficult working with our service coordinator. We learn our legal rights quickly. We pushed hard, make tons of phone calls, and eventually got the necessary services. It was a hard time in our lives but we got through it. Once services, adequate services that is; were in place, we saw tremendous improvement in our child.

This was an incredible program for our family. It has saved us a lifetime of struggle. We wouldn't be the same without it.

First Steps have been consistent and professional. I am pleased!

My son has a speech delay and the First Steps program has been wonderful! I couldn't ask for a better program.

First Steps is a great program. The only thing I found to be an issue or bothersome was the frequent change in service coordinators. It is very frustrating.

Question #7: We had a "developmental therapist"/"special instructor" in our first plan, which was a completely useless addition; she did nothing but muddy the waters by trying to duplicate our PT and OT services. The medical therapists were and remain the ones we needed and need. Attached is a list of my concerns regarding the "teaming" model being implemented. These are the concerns of a parent who thinks highly of First Steps and wants to see the program continue to offer excellent service to families. Finally, my only complaint about First Steps is the paper trail and meeting requirements which waste enormous amounts of money. Why a separate sheet of paper for every tape order and talk tool? Find a way to program them onto a single statement. Why can't the therapists' record be sent via email? Surely there are ways to deal with that, even in the privacy laws. Why require a meeting just to order tape when we run out? This wastes everyone's time and you have to pay therapists for it. These things could save money if addressed.

ATTACHMENT: My concerns about the coming changes to First Steps. I know that they will not affect me, but I believe strongly in the efficacy of the program as it stands, and I do not think that reducing services for those receiving more is in the best interest of the children, the families, or society as a whole. 1. Families WANT therapists in regularly. The therapists are our lifeline. If parents want less traffic in and out of their house, they can choose to do that. 2. New parents depend on the therapists, who are experts in their field, to guide them. They are overwhelmed with information and trying to cope with what is often an unexpected diagnosis. Parents don't know what they need at intake time and they don't have the time or emotional wherewithal to educate themselves enough to find out. They rely on the therapists. 3. If this implements as we perceive, based upon the information we have seen, the therapists, who are our best advocate, will basically be employed by DESE and the SPOE. Thus, they will be limited in advocating for our children, for fear of losing their jobs. 4. Shifting the burden of therapy to the parents' shoulders is not realistic. Parents cannot take over the role of therapist. Even assuming there is time for us to do the appropriate amount of therapy (which there isn't particularly in families with multiple children), we do not have the expertise to reassess the continually changing level and techniques needed. Children are in a constant state of growth and change, and having a therapist come once a month renders that person's time essentially useless. The Parents as Teachers model may work for typically-developing children, but for kids with special needs, there is a constant need for re-evaluation and adjustment, which parents are never going to be qualified to make. We need the therapists for that, and we need them regularly. Once a week is doable; once a month is not. 5. What happens when a child is sick or in a bad mood or overtired on that once-a-month visit? Then it's two months before the therapist can see the child in his or her normal state, and give the parents a valid analysis. 6. Boone County has better services than most counties. We base this statement upon the word of therapists and parents who have lived both in and outside of Boone County, and have seen the difference. We are concerned that by offering a "leg up" to the outlying rural counties, who have suffered from lack of personnel and services, that Boone County will be "legged down". 7. We want to find some way to implement improvements for counties who don't have what we have, without damaging the tremendous work being done here in Boone County.

Thanks for your service. All involved in the program were extremely helpful for not only him but the entire family.

Because of weekly intervention services, I am a more knowledgeable parent which, in turn, greatly enhances my son's quality of life! I will forever be grateful and will share with others the value you're services provide.

Question #8: Dietician should have been offered to us initially with a child with (FTT) weight issues. I didn't know it existed until another provider mentioned it and I then requested it. Question #16: Doctor consistently said our son needed 20+ hours of ABA, but that was not available to us. All therapists were awesome! One of the therapists in particular changed my son's life! He became a different child after working with her. She was so caring and knowledgeable. All therapists at Outreach Therapies have great techniques, attitudes, and are so caring and knowledgeable. I wish First Steps went through age five. Service coordinator need to take a more consistent/active role.

More money needs to be allocated to the program. The program is essential.

I would like to commend our service coordinator for excellent and compassionate service. He's wonderful!

This program has directly impacted my children and my family in a positive way. I could not imagine what we would have done. Our service coordinator is outstanding. Thank you for all the wonderful therapists and activities provided to us.

Local school districts do not respond to children's needs as well as First Steps. We will miss you guys.

The service coordinator is sometimes hard to get ahold of.

We are grateful to our providers for the services we have received through First Steps.

I really love my son's speech therapist that First Steps has provided. I am getting the help that we need. My son has made progress. We are also getting help with other issues that have come to our attention in a very timely manner.

When services first started, both of my therapists were pregnant. When they went on maternity leave it took a long time to get new ones. We finally got a new physical therapist but the occupational therapist we were supposed to get never happened. The dietician slapped my son.

Our son receives physical therapy, but First Steps no longer has a physical therapist that is willing to come to Washington county. We drive to Farmington once or twice a week.

We are waiting for our son to heal from his palate surgery and see how his speech develops before we consider speech therapy.

We have been happy with everyone we have worked with. Our daughter receives physical, occupational, and speech therapy. Our coordinator has been wonderful.

I and my family are blessed to have the First Steps program. Thank you very much and God bless you!

When we began in the First Steps program, I had no idea what to expect. This program is an exceptional program. We have learned so much and our son has come so far. I can't even imagine where he would be if he wasn't in this program. Your staff is phenomenal and I truly feel that they care about my child and for that matter our whole family. Words cannot express my gratitude to all of you and what you have done for us. Thank you.

First Steps is a much needed program for families learning how to cope with the special needs of a child with a disability. The service coordinators and providers teach a parent how to instruct, have hope and encourage the whole family of a child with special needs. Our two kids went through First Steps and we would not have come so far along without this program. Thank you.

I'm thankful for my son's speech therapist. She gave me copies of the sign language she is teaching him so that I can work with him at home.

Since September 2008, when there was a change in service coordination, the new coordinator has made very little effort to be available or to answer our concerns. She has only responded after repeated attempts are made through the interpreter.

The criteria for eligibility needs to be evaluated especially in the speech area. At age 1 my child was referred, but was not eligible, but now that she is, the development in expressive speech is so far behind. It would be better to qualify more children at an earlier age so the gap in development can be smaller and the intervention could be more effective.

Question #12: When my child started First Steps program I felt that the service coordinator was not understanding my needs and my concerns. I received very little support from her. My new service coordinator is a great one to work with.

Good program. Thank you.

Our coordinator is an angel. She has given my family so much hope and encouragement. I do not know what we would have done without her.

It often takes too long to get IFSPs scheduled or to make changes to current services. This caused a delay in getting services we needed.

First Steps is a wonderful program. It has helped my family understand my child's needs.

I would say that...

First Steps has benefited me more than it has my child. My son has surpassed every goal our family has set. It is not vanity when I say it is due mostly to me that he has flourished. But, because of First Steps, I am in contact with coordinators and specialists that have guided, supported and encouraged me to be the mom that my son needs. I was very hesitant at first to accept help from a government affiliate but I am so thankful today for First Steps being available. Thank you for caring about my family.

We greatly appreciate everything First Steps has done to help our family.

I don't think we could have met the needs of our child without First Steps. The program gave us clear direction. Thanks.

We have nothing but great things to say about our First Steps program with our son. Our physical and occupational therapists are FANTASTIC. Thank you for all you do for us!

This program has been great for our child! Thank you so much.

I am not sure what to expect after he turns three and having to wait until 2 months before does not allow us a lot of time to make the necessary plans needed to keep him in what he needs along with scheduling issues for everyone.

If my child wasn't working with Parents as Teachers, I would not have known about First Steps.

My coordinator is very resourceful and not only teaches my son, but she teaches me how to be a better mom for my son's development. I am sad that she will be leaving us soon, but I wish her well and anyone who is assigned to her is very lucky. She always addressed my concerns and provided me with a bumboo chair and a premature baby carseat. She also gives me advice when I need it.

It was frustrating having the service coordinator change multiple times.

Our coordinator has done an excellent job. She listens to what we need and follows through with our requests. Her experience as a parent of a special needs child has definitely aided her in relating and caring for the families she helps. We consider ourselves very blessed to know her and look forward to talking with her every month.

Getting some services has been slow. Took almost a month to hear from a physical therapist. I've been told there is a shortage of therapists for my area.

Our speech and ABA therapists are wonderful! Our child has come such a long way in only a few month's time because of their great work.

It often takes too long to get the IFSP scheduled or make changes to current services. This caused a delay in getting services we needed.

I can't say in enough words how wonderful the First Steps program has been for my son and my family. The therapists have given my family the support and information we need to make our son successful. I only hope that other families are aware of the services that are out there for our children. The only reason I knew about the First Steps program is because I am an educator. I feel that so many more children would not have the delays they have if they'd only participated in this program at an early age. EARLY INTERVENTION IS THE KEY! Thank you to everyone at First Steps.

Thank you for so much help. I will need so much more in the future as my child grows! Everyone is always so willing to assist me.

We feel that First Steps is a very good program. The provider that comes out and sees our child has been a great asset in our daughter's life. She is a wonderful person. Our daughter responds to her and she really enjoys her work with all the children she works with. Thank you for the services.

Overall, the therapists that worked with my son were very good. Although we have one that will sit and text message people on her phone instead of working with my son. I would really like another therapist, but there are no more in our area for special instruction.

This is an excellent program! The staff was always very helpful and treat me with respect. I highly recommend First Steps!

Our child's providers are a heaven send for our family. Without them we wouldn't be as far in our progression as we are. From the start they have been like part of our family. Our son enjoys all of the girls and the new things they bring in their bag each week to learn with. You are very lucky to have such a great team doing great things. I hope to continue to learn how to grow on a daily basis with our son and his special needs. Thanks for all you do and your program comes highly recommended. God Bless U