

## **AMCHP 2007 ANNUAL CONFERENCE**

### **HEALTHY COMMUNITIES**

March 3rd to 7th, 2007

#### **Evidence from a 6-Year Medical Home**

##### **Demonstration Project for CSHCN**

THERESA PETTY: Good morning. So I thought I just start and just tell you about one of the families that we worked with, and this was a family that received our services for more than a year. Typically, the intervention would last in the first project approximately a year and the second. We plan it for six months and then reassessed their needs. So this child was 11-years-old, and he had a diagnosis of severe autism. He was not attending public school, he was attending a states school, and I know where one of the few states that has that system in place for better or worse that's where he was. He had a lot of intense behavioral needs, and not all of which were well controlled with medications, and his parent was a single parent. She had another child in the household, and she had a lot of stress as you can imagine trying to take care of him, and keep him safe, and take care the rest of here family. So that's what we kind of knew going into our intervention with them.

So I'll summarize the intervention, and then as we go along, and I tell you more about each step of it, I will tell you a little bit about what we did for this particular family. So the intervention started with a home visit by the family support

specialist, and again, I'm advanced practice nurse, we also had our registered nurse and a master's level social worker in the second project. We would conduct a need assessment and look at the family needs, and then we developed a written health plan with input from the primary care provider and the family. We provided the family with information and resources that they needed, offered family to family supports, and assistance with complex issues. So what does that really look like for this family?

We conducted a needs assessment, which is a semi structured interview that we developed to identify unmet family needs both in medical and non –medical settings. So we'd set and asked them questions. This process would take just to kind of find out what kind of things they needed, tow hours the longest I ever spent with a family was three and half hours in a home visit. And so we'd set and say, "Do you—does your child need to see additional medical professionals that he or she is not seeing? Do you need supplies for their medical care," that sort of things to assessed their health and medical needs. We would ask them about what was going on educationally for the child, this they have the services they needed in the school setting, was that in place? How could we help to connect them with the resources they needed to meet those needs? As far as mental health supports, that would address both the needs of the child that we were serving if they had a mental health condition or had a need for counseling as well as for the parent and other family members, and many of our families as you'll later, have this type of a need. And then family supports is just kind of where we

couch the basic things, food, clothes, shelter, right because we found that the families couldn't really address these other complicated needs until we help them get in touch with the basic things. If your lights aren't on you probably not going to make it to your appointment the next day. So that was our needs assessment.

When we assessed the child that I told you about, we found out that there were a lot of stressors in the home and the parent felt she could really use some counseling but had a lot of hesitation to access that herself. The sibling was experiencing a lot of stress because of her brother would hit her, and she was embarrassed, and the mom's attention was all with the brother, and mom was very stressed. It was a very chaotic household. There was also a need for some supports in school because the child wasn't able to attend school as often as possible because of the behaviors and in fact, she couldn't even get them into the primary care providers office for a check-up because he had such a strong reaction to being in that office facility. So base on that, we developed a written health plan for this family. And if you'll turn to your handouts, I think it's about the third page in. It has a little picture of a family. The family resources page is the first part of our written health plan, and that is the piece that found was most useful to the greatest number of people that we worked with from physicians to agencies that worked with family, and the family themselves. So that's kind of like a snapshot at one point in time of who all is involved with the family and the child and how to contact them. So family sought that was great, and when we'd send that to PCPs or specialist, they thought it was awesome because it was

everything in one place. And to get that seems pretty simple but sitting in the family's home on the couch with younger child running around, and the parent taking phone calls in the middle of it, and I said, "Why can't remember a name and she," somebody comes (inaudible) but I'm not really sure what they do. And so just to have that organized and put in one place was one step ahead for some of the families we worked with. And then the next page that we used was the emergency information form for children with special health care needs, and that was pretty (inaudible) the American Academy of Pediatrics and the American College of Emergency Physicians, and we used this as part of our health plan for the family so that if they needed to go to the emergency room, they could also use it for the school as part of their emergency health plan, and it was kind of a snapshot at any point in time of the child's medical and health care needs.

Now I would visit the physician practice for primary care and review the notes, and complete as much this as I could before the visit, complete more of it with the family about the emergency contact information, and then it was reviewed and finalized by the primary care physician prior to sending it out to the family so that the things they needed to attend to and treating the child in emergency where accurate. And then the very last page is the child and family plan of care. So based on all the needs that the family would tell us about, we would sit down and say, what do you want to work on for the next six months, and so we developed goals and health and medical, educational, family supports, and mental health, and then make action steps.

Now, this is the final version of the care plan but it went through a big evolution over the years, and this is the simplest one. So we had a big debate, should we include it but the reason we include it is because we finally got it to make it where it was fairly functional for families because people that are busy and stressed do not want to get a 10 page bucket telling you what the plan is, right? But just having a little list seem to be pretty helpful.

So back to the child that we were talking about, what we did for him was we arranged an interagency meeting for the family, and so we set all the providers down and talked about the needs of the child, and the needs for counseling and behavior management. We did find that the family had burn a fair amount of bridges in their time by just trying to pull their things back together and get a plan and place where people kind of start again, and communicating that back to the primary care physician who really was able to see the child. That's one of the things we did for them. Then so information resources was another part of our intervention. Over time we learn that most of the families we saw needed information about basic resources like food, clothes and shelter. We always gave educational resources so we got (inaudible) and finally put it into a notebook and took it with us to the visit instead of mailing it. And then based on the needs assessment, we would gather individualized information that wasn't in our sort of general pocket. We did three repetitions of the resources. So during the needs assessment when I would say, "Do you need any supplies or equipment for your

medical care,” and they go, “Well, my son is 11-years-old, and he needs incontinence supplies.” And I’d say, “Oh, here’s how where going to do that.” So I mentioned at then when I review the notebook, I would mention that a second time, and then when I sent the care plan to them completed, I would mention that to third time. So they heard it kind of three times which falls the basic education principles. We learn this at nurses, right?

And finally, in the project, we were able to actually take a laptop printer, so we’d made that list together, and the goals, and could print it out a give it to the family right then and there. So because what I was doing is to get my legal pad and I write the list, okay, first, we’re going to ask your doctor to write an order, and then it was just right there for the family to have. So the family to family supports were another really important component for what we did for our families.

We had a parent consultant as member of our staff, and it started as part time, and then went to really full time. They—I still hear Dina O’Brian’s voice in my head saying, “The most important need of families is information,” and I think about that everyday as I’m working in a different setting now seeing kids in clinic. She gave us input on family centered care from the way we handle the needs assessment, the initial phone calls to the families that were referred to the way that we presented the information back to the family. So throughout that process she helped us make sure that we were meeting the needs from a family perspective. She also did outreach toward families or phone, and personal

contacts. She developed a news letter which was sent out. She maintained a (inaudible) for the families where she sent information, and where they could communicate back and fourth with each other wince they were across such a wide 16 county areas. So a maximum of three hours to the north, three hours to the south, two hours east and west was kind of our coverage area in terms of driving time.

And then we had family events which range from family nights where the whole family was invited. The sibilings and the parents, so they could get together and we also then later did some sib shops with our social worker, and then the parent was really like for the families that were really hard to reach like his family I told you about, what she did was she actually help the family plan for the appointment with the provider so she could think of all here questions, and this mom didn't make list but she help her think through it so she (inaudible), she attended the appointment with her so she could help attend to the needs of the child while the parent communicated with the provider. She called her afterwards to talk about, okay, what did you think, how did it go, do we answer all your questions, and also the same with the inter agency meeting. So the parent actually felt that she had an advocate right there because our parent consultant really could relate to here in a way that we could not as professionals. They had a bond almost immediately and we found that it was a huge thing. And then this family was kind of hard to get to follow through but Dina could say, "Look, I know what you're going through. I've been there myself, and so let—this has been helpful for me. What

do you think about this, and it wouldn't be a threatening as given the information.” And then the assistance with complex issues, I think we've talked about the enter agency meeting that we held for this trial, opening up the lines of communication among the providers, schools and agencies. So often we might here something from a family and a home visit that they hadn't told their primary care or specialty care provider about. And then when Dina would go back and call them on the phone to offer family support she would hear things that they didn't tell us in our two and a half or three hour interview. So just having the time to seat and talk with families and multiple points of contact really enabled us to learn more about the issues that the families were dealing with. And then here are some of our families.

Another example I'll give you something how we worked with the family. We had a three-year-old who had a really rare genetic condition and she said, they were only—she was one of the five people in the world that ever had this condition. She's not in this picture. But then I have to remind myself that every child is one a million, right. So there's one of every kid that we see in every family. And so she had a neurological component to her condition that was life threatening, and she needed a surgery. That was the one thing that might help save her life. That wasn't available in our state. So her parents, they have a lot of support (inaudible) at home nursing, and in home therapist (inaudible) three program was in place, and they actually researched and found something that they thought could help here, and we were able to assist them in arranging transportation. So

getting approval to go out of state for a service that was necessary, and then arranging the transportation to get her there. We raised the funds before the approval was given, and so they had an opportunity to communicate with that specialist..

THERESA PETTY: Right, well, having the high stress of mental health needs in this family's case was a little bit different than chronic for persistent mental illness, which some of our families had, but I think it was just the many years of stress and just not—getting a plan and then not having the energy to follow through and providers and agencies we get really frustrated. Yes.

UNIDENTIFIED SPEAKER: Can you give us some little better picture about this (inaudible) of your program? Do you have nurses assigned to particularly to have a continual practices you may have (inaudible)

THERESA PETTY: We started with one nurse and then when added a second nurse and then a social worker, what we found was that, the families where children had more emotional behavioral needs identified from the (inaudible). When we got the referral, we would refer to our social worker but now we'd—our—and so that was one way that we (inaudible) our case load when had three people, otherwise now we want to cite the different practices. We would just go and meet their needs the best that we could.

UNKNOWN SPEAKER: So it's basically just a recall of these programs  
(inaudible) for most complex

THERESA PETTY: Yes. I think that in their interest of time, we probably need to go and move on but we'd loved to answer more questions as we get through.

JANET FARMER: Perhaps this will also answer some of your structure questions. In the first project, we were involved with three primary care practices that serves children from that nine county area. And you're right, what you—how you describe, it is a referral system as correct but we—these three practices that we started with—where university affiliated primary care practices, so basically we started working with our friends in the first project, again because we knew we had so much to learn, and in terms of the program evaluation, we're calling this study one. It's actually the period that was funded by the Robert Wood Johnson Foundation Money. We actually enrolled a hundred children, but when we started doing the analysis, we realized in (inaudible) sight we'd enrolled siblings of some of the children, and so we dropped these siblings from analysis. So we ended up with 83 children enrolled from nine counties referred by these three physician practices. That included the 11 providers, 10 physicians and one nurse practitioner. And so that's not a lot that we had to deal with, and they gave us a lot of feedback about how to work with their practice.

We actually started out thinking that we would get time of the physicians, and we did. On the other hand what really made this work was we found a key nurse to each of these practices, and ended up doing a great deal of work with the nurses, nurse to nurse type of communication about these children. The physicians were available to provide oversight and to really—if they were any significant questions that we had about how to manage or help them manage the care, we certainly did access the physicians. Boon in fact, I can't underestimate, excuse me, the amount of time that spent in teamwork, and that the teamwork made this successful. So as Theresa mentioned in the first project, we followed families for 12 months. We had a very simple evaluation design, and it was just a pre-post evaluation. We gave the families a survey prior, and we also did chart review. We won't be able to read much of this but (inaudible) to say, we used measures in the study for the parents survey that were available at that time, and they were actually ended up to be quit strong measures that were sensitive to change. The New England serve the shared responsibilities (inaudible) came out of upstate in New England serve project, and that was a very major part of our assessment tool. We'd look at family needs not just through their—this semi structured interview but also in a paper and pencil report from families. The impact on family scale, many of you might be familiar with that, it assess family strain and burden related to the child with the special need. You'll find me never saying burden again through here because our family—our parent consultant told me that that was not a good word to use that families didn't like to think of being burdened by their children. But that strain was a far more acceptable way of

referring to this. And so we did learn a lesson there from our parent consultant even in those kinds of semantic issues.

The functional (inaudible) is a measure of or excuse me to revised form as a measure of child functioning then the family supports scale is just what it sounds like, and then at the end we had a satisfaction scale that we gave about have family—what family is like to about what we've done. By the end of the year, we had 51 families who completed a survey for us. So we start out with a hundred at time one, dropped in down to 83 in terms of our analysis, and ended up with 51. So this is not uncommon in evaluations like this to lose families over time, so we have about a 50 percent little better than 50 percent return rate. But what knew was that, the kids on average were around seven years but were had to full spectrum from birth to—through 17. In fact, some of the kids aged out in to being 18, and so before we were done, about half were boys and Boon County were primarily—and in this region it's primarily Caucasian. So the fact that it's 67 percent Caucasian as actually—we had more minorities than would be represented in our area typically. Probably reflecting the fact that there are more children with special health care needs, someone minority family's, and then diagnosis. These were involved children. Let me just say that simply. On average they had two diagnoses but 71 percent had more than one condition. We had to range up to seven different conditions in one child or actually several children in this. Can you imagine seven conditions? How crazy. I mean as a parent, trying to keep up with the many needs of a child with seven diagnosed conditions. We had

a whole spectrum here but I wanted to call attention to a couple of things in this project. The number of children with mental health concerns was relatively small but the number of children with what we call organs specific comprised the largest group so that was kids with kidney problems, cardiac difficulties, a single system kind of chronic problem. And then on the functional measure, 63 of the children in project were a bit low the functioning level of most children with special healthcare needs.

Now, the families—may of them were low income, as you can see not quite half reported less that 20,000 dollars of income in a year. That number was always so striking to me. It was just almost hard to imagine what it would be like to try to manage these complex children with such low income. However, in this particular study, we didn't have just low income families. There were families across the income spectrum, and I believe well up into the 60, 70,000. In other words, this is not just—having money is not the only thing that you need in order to take care of children. You can have lots of money being able to provide a lot of things, and still not know how to navigate the system of care. These were pretty well educated families. Eighty-three percent had at least a high school diploma, still left a fair number without--the family structure was about 30--a third of them had single parents--I'm sorry, that's my phone. You could pull it that way. I should have shut that off. Sorry. So about a third were from single parent families, about half lived in Boon County. Aren't you curious who that is? Sorry, about that. So about half lived Boon County, and the others were from the adjacent counties

around us. And then we didn't limit kiddos on the basis of type of health insurance. So we actually ended up with a pretty even distribution of families from Medicaid fee for service which in Missouri (inaudible) Medicaid. The Medicaid managed care company had about a third of the kids from there and about a third from commercial. So again just having adequate income, and a primary--all these families had primary source of care that was not enough. They still needed help navigating the system of care.

Here's a kind of a little slice of this first project. On average, families had nine needs but the range was up to 25. I don't know who that one with zero because to tell you the truth, this was on a paper and pencil report not by interview, and there was a family enrolled that ended up not having a need that what we learn very early on is that you have to use some system besides going in the same and tell me what your needs are. Now, that may seem very simple to you all, and obvious but on the other hand it took us about six months to figure out that we needed the semi structured interview. And once we got that, and took family, and didn't say what you need, but say, "Tell me about how things are going in terms of your child's healthcare. We got a whole different picture from families but on this paper and pencil measure what we learned was that families needed information about services. We knew that. Mental health was a huge issue. And it's pretty well-known. I'm not sure how it is in your state but in Missouri it's pretty well known that our mental health system has been broken for sometime, and there's a lot of effort to try and improve that. There have been over the last 10

years. And then the need for care coordination, again, for example, you'd have a family come in with the child with a developmental disability who'd never heard of the zero to three program, who had no idea about the department of mental health regional centers, and the physicians didn't always know about those things either, and so part of our role was to help with that. The family said had more met needs. This will come as no surprise to you but the families' minority groups, and there's probably a number of reasons for that. The families who were at lower socio-economic statuses, the parents with lowered social support and the parents with higher perceived burden.

Based on that sample of 83 that we started with, we looked to see what predicted the number of needs, and what we found was that it was not the Child's level of disability. It was not the child's level of disability. It was the families need for support that predicted the number of unmet needs. That surprised us. In fact, we looked socio-demographic factors had to do with unmet needs but the child's level of functioning or the child's diagnosis had nothing to do with number of needs. And since then, many other things have come out to show that family needs are not always associated with the child's level of functioning. It's more about family support, and also how the family looks at their situation, they're perceived—look I made that area. That's an old slide, that's why I apologized. That level of strain, the perceived amount of strength. Now, here was what we found in the first study. The intervention that was provided, resulted in improved satisfaction with certain services thankfully care coordination because that's what

we set out to do was to provide and improve care coordination through the medical home, and indeed, over and over again in these studies that came out as being different and improved. And then, to our surprise but also to our pleasure, the satisfaction and the amount of access to mental health services. So because the mental health system was one of the harder ones to navigate, I think we had more impact there. We had some knowledge. It wasn't always easy for us either. In fact, it was sort of a moving target in terms of health care systems, and we had to keep learning over and over again, how to help families navigate the system of care. But we were able to get more families into needed mental health services. In terms of child and family outcomes, this is what families told us. They had fewer needs, they felt less strained, parents got to work more often, and kids got to school more often. So, that just pleased us no end because these were the kinds of things we were hoping to accomplish. There was no difference between families who lived in the metropolitan Boon County area and the more rural areas. And so that was interesting too. It's more about who the child is and who the family is than where they live. It seems that families even in rural areas can get to the services that they need if they know how to get there and have support to do that. And 95 percent of the families rated the intervention as helpful or better. I think it was more like 80 percent, so this intervention was very helpful or extremely helpful. Now, that really surprised because the one criticism we had from the moment we started this was that we were just duplicating other services that were out there. Again, the issue of multiple care coordinators, but in reflection on that what we think was different is that those other care coordinators

were usually from a silo. They were usually from the Department of Health or the Department of Mental Health, and what they were trying to do was to plug a family into the services that they had available. What we did with this project in collaboration with physicians and nurses and the practices was to step back and look over the whole system, what could they access and how could they get there. And so, I believe that's why this project was especially well-accepted by families.

Here's a slide that shows the change in family needs, and you weren't going to be able to see this, but the impression I want you to take away from this was that they were categories of family need, information support, explaining to others, community services, financial needs, and family functioning, and every single one of these categories went down. Particularly the support, the decrease was significant statistically in terms of support financial assistance and family functioning.

UNIDENTIFIED SPEAKER: (Inaudible).

JANET FARMER: Parent surveys. So this is all parent report. Well, you can see after looking at this with us is that there were limitations to this first study, and the small sample size, the limited number of primary care practices in just three practices in three areas in the nine counties. We didn't have a comparison group, the pre-post design is an okay design but it's not the best in the world. And then we didn't really have an appreciation or didn't really measure the impact we had on the system of care. And although we actually have Medicaid cost data from the first study, it was all advocate data, and we found it between the small sample, and the fact that it was just advocate data we didn't find it terribly useful. We haven't given up on looking at it yet, but it wasn't exactly what we needed to look at cost savings.

So then in the next period, the period that was supported by the Missouri Foundation for Health, we made changes, and in particular, we saw a lot more children. Part of this funding that we had was actually for direct service delivery, so over the three-period we worked with over 300 families, which was really eye-opening, and helped us learn a lot more about what—how many differences there are between families and between children and their needs. But the key thing was we expanded to many, many more providers. And so what we did was we partnered with the Missouri Care Medicaid Manage Care Organization and all of our referrals came from the manage care organization. And we had there an entire network—we had instant entrée to the entire network of physicians that they had in 16 counties. That's why 16—in case you're wondering why 16

counties? It's because that was the (inaudible) for this manage care organization. So, we ended up working with 129 different providers and children—again, referrals from these providers to us. We improve the program evaluation, and then we also worked with the Department of Health to develop a statewide medical home training program. The participants that were referred from the Medicaid Manage Care Organization were similar yet different from in our first study. Well, it doesn't say that. But in fact, we enrolled 100 children into the evaluation arm—over 300 we saw 100 we put into the evaluation arm. By the end of the year, we had seven date remaining. Okay. So we had a little bit of retention this time. And age was they were about the same, birth to 17, the criteria were the same, by the way. The only different was that we got smart and we—well, we got smart because nationally we had a new tool and that was the CAMI screener. And so, well, that's what we used for physicians to be able to screen for a chronic health condition. We use the CAMI screener as an entrance requirement. Yes.

UNIDENTIFIED SPEAKER: (Inaudible).

JANET FARMER: And what a good question. We haven't looked at that. But yeah, sure. You're absolutely right. We did have more mails, and it was striking the difference in mental health—children with mental health problems in this study. So, remember before we were working with three primary care practices and referrals from these, now we're working from a whole network of Medicaid

(inaudible) only. And we got a huge amount of kids with mental health problems. The organ specific went down from 37 to 27. Prematurity in the first study was 30-ish percent, and it was like four percent, and I know I can't explain exactly why that is. Perhaps because the physicians in the first study were connected to the university and we do a lot of care of mothers who are at high risk and have premature babies. Perhaps that's why they got sent into those practices. But there was a markedly differently appearance to the kids and families in this project. They were severely involved in terms of their functional level, and from the county 71 percent of them met increased service needs, function limitations and medication use. That come altogether. Mm-hmm, yeah. So that shows you how well-severe—how involved these children's needs were.

I'll have to look at your question about is there a relationship. The numbers of boys isn't that much higher. I mean, it was 57 percent to 66. Yeah, I mean, 63. I think it's probably a different sample entirely in some ways that we're looking with because they're all low income.

So remember before, John, I'm not sure I can remember exactly, but 75 percent, it was like 47 percent before—we're below 20,000, in this sample 75 percent were, fewer had high school education, there were many, many, many more single parents here. Well, it's 35 percent before and now it's 69 percent, and 100 percent were in this Medicaid—enrolled in the Medicaid Manage Care. And one thing we did remember to do in this project, we added in a measure of

depression. This is the back depression inventory case, you're familiar with that. Thirty-five percent had moderate to severe symptoms of depression. We're not doing a clinical interview to say they're depressed. These are just symptoms of depression, but that is a huge number who score way up high on the back depression inventory, and there were many others who had milder symptoms. Yes.

UNIDENTIFIED SPEAKER: And was that the parent?

JANET FARMER: Yes, yes. This is the parent. Right. And here's what—in this particular sample, this was based on interview, right? Yeah. And this particular study we also took data from the interview that needs interview, and this was the—there weren't any limitations in the interview on the number of needs families could tell us about. So, you can see 58 percent told us about more than 15 unmet needs, and these were not small needs. These were large needs. And then another 27 percent, eight to 14 needs, and then sort of the winners and the group had six to seven needs. So, you can appreciate—we had to do a lot of helping each other with just straight stress management. I'm talking about the family support specialist and the parent consultant because this was really stressful work to try and take care of these families. But they're under tremendous strain, but we felt that, too, in terms of taking care of them. And so, in terms of the program evaluation with the second study, we enrolled the first 100 children from the Missouri Care enrolled. We would've done more. I would've

loved to have done more with those 300 families in terms of evaluation. But they were upper limits in terms of the amount of funding. We had to be able to collect data, so we did the best we could, and that with the hundred. In this case we randomized families to treatment or to a (inaudible) control. And I'll show you here in a minute the design. But this was really critical because we actually had a randomized controlled study of this intervention this time. We shortened it to six months of intervention, although families who had six months had the option to continue, but only be telling you about six months worth of intervention. The previous study was 12 months. And then we did the same format for the evaluation. We did a parent survey plus chart review. And here it just shows you on the parent survey, we picked up the new version of the shared responsibilities tool kit. We used the CAMI for pulling kids in and we added the back depression inventory, but otherwise it was very similar.

Now, here's the design. So we had two groups, group one and group two. Group one was the one that received the intervention immediately. Group two was the group that had a six months waiting period. Okay. And in terms of—I don't have my (inaudible). So, we looked at pre to post here, pre to post here, and then we looked at pre to post here. Okay. But we also looked at between group here. Okay. Let me say that again into the microphone here. So, we looked at pre to post for the intervention in group one, which is the dark shaded area, from time one to time two, and then in group two, we looked at pre to post from time two to time three, which was their first six months of intervention, right? But then we

also looked at the groups, the treated and the untreated groups, after six months. Now, I want to tell you that when I present these data, we collapsed across group one and group two during their—for the data analysis that I'm going to present to you, because both group one and group two looked almost identical pre to post, and there were no differences between the groups after six months of treatment. And so, in order to increase our sample size, we collapsed those two groups so I can tell you—so we could pull out the main points of what we were seeing, and I want to talk about those first. So, this is just again saying pre to post differences after six months of intervention for group one and group two collapsed, that ended up being a total of 61 families, and then the between group differences after six months of treatment, group one versus group two because group two was untreated, and we had 70 at that point. So, any questions about that design? Yeah.

UNIDENTIFIED SPEAKER: I was wondering, did that have anything to do with some of the symptoms which had—because you never mentioned that had—certain ways that had a family where they have a children of (inaudible)?

JANET FARMER: Actually we got a little smarter in this study. We didn't enroll siblings, and so the decrease in numbers that you see is due to a number of things, moving out of state, unable to contact. We have a lot of that information about what happens exactly. We have all the information. Very few families dropped out simply because they didn't like the project. It was not being able to

find them. These families with low income, it's well known that they're hard to track overtime. Did that answer your answer your question?

UNIDENTIFIED SPEAKER: (Inaudible).

UNIDENTIFIED SPEAKER: The siblings in this study were limited. We had the group that was involved in the evaluation, and so if there's a sibling that needed services, we put them (inaudible) clinical side, so they (inaudible) the data but they doubt the service.

UNIDENTIFIED SPEAKER: So you'd see that's what I was concerned about because you're saying it's a family effort and it's a—it's not (inaudible), so you would want to treat everybody (inaudible).

JANET FARMER: Yeah. Well, but we just collect the data on one of the children if there was more than one in a family.

UNIDENTIFIED SPEAKER: And why would you (inaudible), I mean that's kind of like—to me it would be kind of you're doing (inaudible). (Inaudible).

JANET FARMER: Okay. Yeah. Clarification question.

UNIDENTIFIED SPEAKER: And did you consider looking at the--between (inaudible) at the end of 12 months to see if there's any lasting (inaudible) in the first group?

JANET FARMER: We did. Yeah. I don't have it up here but I can talk about that if you like. Okay. So, while we've been talking you've probably been reading, what we found from the pre-post analysis of the 61 overtime was that, again, very much like the first study. We saw improved satisfaction with health services particularly care coordination. That came out really strong. But then in addition to mental health we also saw improved satisfaction with specialty care and with therapies. In addition to that, we saw decreased family needs very, very much the same as before, needs for information went down, that's a good thing, right, needs for information going down, needs for support went down, so support improved basically it's another way, and needs for community services—unmet needs for community services went down. So, we're seeing a picture come forward here, improved satisfaction by the families, decreased needs, and decreased family strain associated with it. In addition to that, this time we threw in the real simple poor to excellent rating of child health, and we saw an improvement in that overall health rating. The school absences went down again. We didn't see a strong in effect on parent work. I don't know whether work attendance—I don't know whether that was because of the sample, we don't know, but we didn't see that coming forward in this study. We saw this trend of (inaudible) 0.06 toward improved child functioning out of this group, a trend

toward improvements and parental depression. Remember now, we weren't doing cycle therapy. They may have gotten into a mental health setting because of the care coordination efforts we were doing, but we were not specifically treating depression. And again, as a psychologist, this was my feeling was that families were so stressed and strained by the system that they were ending up depressed, and if you change the system for them made it easier. Would you see improvement? Perhaps. We can't say that's why this happened. But again, there clearly was a trend in the direction of less depression, less depressive symptoms. And again, no difference between urban and rural. Okay. So that's the pre-post for both of those of groups. When we did the between group findings, these are the most pristine tightly controlled results because we washed out all differences at baseline. Actually there weren't randomization took care of differences, but we also controlled for many different things. And so, and the most pristine well-controlled analysis, the impact of the study is on improved satisfaction with health services, especially care coordination and decreased family needs, especially in the area of information. Okay.

We talked to our statistician a lot about where to put the white and this—between pre-post or the randomized between groups, and we agree with him. He said they're both important. In the pre-post you're looking at—you're starting where families are and seeing how they change, and that's very important. And this one, you're just looking at the between group after you controlled for everything, and it's also important. So we believe presenting both of these is important in

understanding the impact. Parent satisfaction, exactly the same as the first study. There's a few families who don't care for this, very few, five out of 100. Well, no, that's not right because we go down to 70 by this. But anyway, again, most rated this as very helpful or extremely helpful, and they things they liked. They loved having more knowledge about where the resources in the community were. They really like the written health plan. We were surprised by that, but it's a written health plan, but they really like it because they could use it to advocate for their child. And so we think that was very effective. They really liked the assistance communicating with the physicians. And so the interagency meetings or the team meetings where we had the specialist and the primary care physicians all coming together, they felt like that had a huge impact on their child. And then support from the family support specialist, so the actual relationship that they had with the people who are helping them, and the newsletter, which was the parent-to-parent connection that they had. Now, the physicians, well, those physicians, they didn't really respond to our survey very well. (Inaudible) too surprising. So, we got a 44 percent return rate from the physicians and, of course, this is probably by a sample, but the ones that returned they all loved it. So 100 percent reported that they really liked the intervention. The things they liked about it, they really liked having someone to go to the home, because these people are so—these families are complex, and having somebody in the home, they felt like they got better information back, I think probably. Identification of unmet child and family needs, so what they couldn't get in a short-office visit, this approach was able to provide to them linking families to resources just like families—this was one of their

favorite things, too, so helping families get connected. And then the assistance with problem solving about complex issues, they also felt that was quite impactful.

So I'm getting ready to shift gears here. I think in terms of interest of time, what time are we supposed to (inaudible)? 12:15, we got another half hour. I think I'm going to keep pressing along and shift to talking a little bit about the systems issues that we saw. But please write down your questions so I can come back to those.

So what kind of systems change did we make? Well, it's impossible to measure. On the other hand, there was a large movement coming in at this time related to the medical home, and a great deal of interest in the department of health in helping their service coordinators become more familiar with the medical home. And so what we did was we partnered with the Department of Health, and first of all, we assessed all their service coordinators for what they knew about the medical home, and provided that information to the department, and then out of that we developed training materials. Some of the training materials we used were from the AAP medical home training materials. They were very, very helpful. And then what we did was we took the forms in Missouri that the service coordinators were using, and actually built in components of what we had done in our intervention into their materials. And so, we took those materials then and actually trained them how to use their materials in a way that would support the

medical home concept, beyond just making that a child had a primary source of care, but also this team approach to partnering with the physician and addressing child and family needs. They videotaped that training and they've since disseminated it for new—well, I guess I don't know exactly. This has been about years ago that they were doing this. And they took it and they took it to the next level. So they took what we had done, the Department of Health did, captured it, and I believe built on it from there. Anyway, it was an impetus for change in health service coordinators approach primary care physicians, and we shared a lot that we've learned with those 129 physicians, how to get in, how to partner with their nurse, all those kinds of things. And then the one other thing that we did that we've been really pleased about is we actually have incorporated—we have a (inaudible) project at the University of Missouri. It's been there since 1995, and we incorporated the needs assessment, semi-structured interview, and to some of the work that we've been doing with our trainees. So when they start working with families, one of the first things they do is go through the needs assessment with families, and that's worked rather well.

UNIDENTIFIED SPEAKER: (Inaudible).

JANET FARMER: Yeah. Leadership education and neurodevelopmental disabilities, it's the Title V program--maternal and child health program rather that we bring together--I believe it's 11 disciplines, and they trained together for a year. There's 11 or 12 faculty members and just as many students who train. So,

every year there's about 08 to 10 to 12 students who complete that program, and they are now being exposed to the medical home and to the materials we used and to the approaches we use to work with primary care physicians.

So, our challenges. In terms of child and family outcomes, some of this was a challenge or it's just a great deal of effort. In terms of the parental depression and the many family stressors especially in the second study, we were not always prepared to meet all those needs and to help families. And the parent consultant was, again, a huge part of getting to families that were just so stressed out that they couldn't even begin working with us. And so there were a couple of families that we just sent the parent consultant in first, and that was a nice solution. Along the way, here we were trained to coordinate services but there were cuts in Missouri, major cuts in services. I'm sure there were in your states, too, during this time period, and we found that to be quite challenging, something that was pretty much out of our control. We still try to patch together. We ended up having to rely more on informal support sometimes as opposed to formal professional supports. But we got pretty creative at times in terms of how we would approach this with families. And then in terms of the systems change in trying to make differences across the state, the building new partnerships with practices and primary care physicians, some welcomed us with open arms; some just didn't have much time for us. And we never really have gotten to the place where we could tell one from the other it would be nice if we could determine, sort of, what it was about those practices. But we do know the practices in rural areas were

more stressed and have fewer staff to be able to relate to us. But again, it wasn't so much about the practices, their size; it was about the people who were running them, right? And then sustaining partnerships with the Medicaid Manage Care Organization. It's been effortful, but in fact, that is the continuing funds that we have for this project now that grant funds have dropped a way. The Medicaid Manage Care Organization continues to support a part of a position for us. And so, that was how we've sustained the project was through them in. Of course, they were hoping for cost savings, and they really—we don't have the best data on that yet. I can talk more about that. But they know specifically that the case is where they've saved a lot of money by having this kind of support for families. And then the constant challenges, how do you sustain this teamwork approach, how do you fund people to do this?

The lessons we learned--just to recap a little bit--the lessons that we learned. It takes a team, multiple stakeholders, in order to create individual change and systems change, building consensus about the child and family. So much of what we were dealing with early on was of complete focus on the child. And I believe what we did with this project was to open the spotlight further onto family needs because most of the agencies were not asking about family needs. They were asking about child needs, and that's what they're funding to serve. This project, I think, made a difference because we looked at the whole family kind of what this person over here has been getting at, is, well, you got to look at the whole person in the medical home, and I think we were successful with that. We found very

quickly that you had to not only engage the administrative people, the Department of Health, the Department of Mental Health, and education and so on, but you had to attend to the grassroots issues, what was happening in that specific practice for that specific child, and how did you get in, and again, this door through to the nurses in the practices was really a revelation for us. (Inaudible) how important nurses were. But really, so we tapped into the internal partnership and practices, and brought our team to help them. And then obtaining data, it's made a lot of difference for us to have these data no matter how small samples and all that kind of thing, but the data has really made a difference in terms of being able to make some changes. And then I believe we were opportunistic in a good way. We took advantage of some of the relationships that we built, and key people that were great supporters of this made worlds and worlds of difference. You never understand—underestimate one physician like Dr. Silva who could influence a great number of people. One of the opportunities that this led us into actually is our new Thompson Center for autism and neurodevelopmental disorders. This center started in—we received a large gift from a donor to start an integrated system, care system, for children with neurodevelopmental disorders. And now what we have under one roof at the University of Missouri is our developmental physicians, all of our psychologists, all of our educators, our speech language pathologists and so on, under one roof, and families can come and do one-stop shopping. And so we're still—we now have a new organization on the University of Missouri campus to serve families and children and youth affected by neurodevelopmental disorders. It's

been a wonderful thing for us. And then future directions, there still remains this question about, is this cost effective? We actually have Medicaid data on individual children now from the second study that we need to try and take a look at. But unfortunately, it's still really small sample, so even in the second study we had 100 children, but we're going to be doing some preliminary looking at that. But you really need a much more large scale in order to look at cost data. If anybody has ideas about that we'd welcome that. And then there's a lot of things we still believe we could to refine the intervention. For example, there's the question of how do parent sustain that written health plan, the emergency information form? We believe that could all go electronic—and it used to be 10 years ago we're worried because many, many families didn't have access to computer. We're in a completely different information age now, and the percentages of families that—they may not have a computer but having access to computer is entirely different now, and so we believe this would be an opportunity to help families sustain their own child's information. And then we know there's different subgroups of families. In other words, there's families with different levels of need, but we don't yet know how to define those. We actually have some ongoing studies about how do you group families into different levels of need. And it's not always about the number of needs they tell you about, it's also about their circumstances, and so we're looking into that. And based on those subgroups, we're looking at hybrid models. How can you provide a less intense intervention in combination with the primary care physician to the families that truly don't need as much, but being able to know upfront who's going to need

more or less still remains an unanswered question, so we're working on that. And so then this—it takes a cast of thousands to do this work. This is actually doesn't—I ran out of rim on the slide. But this is the majority of people who've worked with us. The people on the left are the actual people who did the work, and then the agencies and groups that we consulted with are on the right.