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Evidence from a 6-Year Medical Home

Demonstration Project for CSHCN

JANET FARMER: Okay. Thank you. Good morning. We're here to talk about the medical home model and evidence on whether it works for children with special health care needs. I'm Janet Farmer, and here's some information about me. I'm a professor of health psychology and child health at the University of Missouri, Columbia. I'm also the director of the Thompson Center for Autism, and—excuse me—and Narrow Developmental Disorders at the University of Missouri, and with me is Theresa Petty. And Theresa Petty is a nurse practitioner who is in the Department of Child Health at the University of Missouri, Columbia. But she's much more than that. She is my colleague and friend, and so we're really happy to be able to talk with you today about our project which is we named the Missouri Partnership for Enhanced Delivery of Services but none of us could ever remember that. So we just go by MPEDS.

I put this up on the screen here knowing full well that you—I can't imagine there's anyone in the room who isn't familiar with this definition. My point here is that, we started the MOPEDS project prior to this definition. So I started writing grants for this project in 1996 and 1997, and was actually quite dismayed that I didn't have this sooner, and quite relieved when it came out because it's been very helpful to

us in explaining what we are and what we do. Just again historical facts, this is data from New (inaudible) in 1998, and so to take you back to when we started, there was a lot going on for children with special health care needs but not very formalized, and this early data coming out showing that 18 percent of US children had a chronic health condition that were shocking to many people, that seven percent experienced limitations in their everyday functioning, and that 10 percent of this children accounted for 70 percent of children's health care expenditures. Now, today, these numbers are quite well-known to us, and variation show overtime. They've changed a little bit but it certainly set the stage for what we were going to do with the medical home. But at that time there was little known about family perspectives or provider perspectives on what was needed. So when we started this in 1998, we started with the year planning, and what we did was we had focus groups back then with families and providers, and found out the things that are well-documented now in the literature. For example, families are always beset with trying to navigate their way through the system of care; they lack access to not only medical services but behavioral, educational and social services that they needed. The system was fragmented, and really by training I'm a psychologist, I'm a clinical psychologist, and so at that time, I was in practice in a rehabilitation setting both in-patient and out-patient, and all I was hearing from families was not how much strain they were experiencing because they're child had special needs but how much strain they were experiencing because the system of care was not responsive to their child's needs. And so I was seeing a great deal of distress, so much so that after hours, and hours of

sitting in rooms with families, that it drove me to write this project on how to improve the care of children and families. One thing that the families noted repeatedly was a lack of care coordination, and again, I'm certain you all know about these things but the thing that struck us back in the 1990's was that families had lost of care coordinators. Many families had seven, eight, nine care coordinators but they didn't have coordinated care, and so one of the things that we were setting out to do was to see if we could fix that problem.

Now, the physicians were just beginning to hear about the medical home model at this time. Remember that, that was really started back in 1992 with the American Academy of Pediatrics. So even in the 90's when we started—the later 90's when we started working on this, many physicians hadn't heard of the medical home idea but when they did they were shocked and dismayed because the demands that they felt were being placed on them were extra ordinary. They lack information about chronic care management for children and youth with special health care needs. They lack time that was a huge issue, time to coordinate care with across all of the specialist and schools, and agencies that the families and children were involved with, and they lack reimbursement for care coordination. In Missouri, that was really striking that the reimbursement for care coordination at all was low, and then to put new demands on physicians just sort of sent them up to wall. In Missouri, we were talking to two groups of primary care physicians, by the way, one was pediatricians, and the other was family practice physicians, and actually there were more family practice talks in the rural areas of Missouri's

than pediatricians. So we had to just focus generically on primary care practitioners with this project.

Now, I'm going to show you a map here in just a second. I'll probably would be handy to show you sooner but Missouri does exist out in the central part of the country for those of you who are from the coast or usually considered the fly over state for many people but we're in the center of Missouri Boon County is where the University of Missouri is, and it's a fairly metropolitan area although many people laugh when I say, well, the county is about 150,000 and people don't really think if that is metropolitan but on the other hand it is, and it's not a bad place to live if you ever want to come and visit but you don't have to go very far to get into rural areas, and so we were also wondering, "Are these circumstances for families and physicians worse in rural areas?" We knew that there was more poverty in rural areas, fewer children with adequate health insurance, and certainly greater demands on primary care physicians. They were just barely (inaudible) out and getting by if they lived in rural areas. And so we were concerned about adding new demands on to them through the medical home model.

So the big picture was there was a significant impact of the why the system of care was working on families or not working for families. We felt there were unmet needs for services and supports. I mentioned the family strain that we were observing earlier. We felt that the culmination of this was a decrease in

health and functioning for children and youth, and that there would be increase utilization of high cost services like emergency department care. And so all those things fed into our decision to take a closer look at the medical home model, and see what we could do to actually effectively implement it.

Now, again, you all know this month, I'm sure of the medical home, but the way we looked at it, of course, the medical home is not a place but for families who are having difficulty navigating the system of care, this is a road map for effective care and services. Care that would be acceptable--accessible continuous family centered comprehensive coordinate community based, that was really important where we are thinking about rural areas, how would that be community based since specialty care was only in the larger cities, compassion and culturally effective.

So we began the partnership, the Missouri Partnership for Enhance Delivery of Services of MOPEDS, and it's hard to imagine that was 10 years ago. Over the last 10 years, six of those years, we actually had collected data, and that's what I want to focus on today but before we do that we want to tell you a little bit about what we actually did.

Our specific games were first to enhance the quality of chronic care management by primary care providers, and then to reduce unmet needs of children and families, and finally we were pretty grandiose looking back. We thought maybe

we change the system of care and improved that, and in fact, in some way we have. And I look forward to telling you about that.

Our history was, in 1998, we received a Robert Wood Johnson Foundation grant, and we were also supported to some extent by the Missouri Department of Health and Senior Services, which is our department of health, and that's where the Title V--our Title V program is housed. Is Melinda Sanders here by any chance? I wasn't sure if she could make it. She's, the person that we've worked with by a great deal in the department of health. And then--and the next phase of the project, we had funding from Missouri Foundation for Health, and from a Medicaid managed care organization who actually had been our partner through the whole period that we--we're doing this project, and the name of that health plan was Missouri Care Health Plan.

The children we were interested in--we took a lot of time initially trying to figure out who we should focus this project on, and every physician that we talk to said, "Please, leave this definition as broad as you can so that I can refer families to you that really need this help, " and so we did. Basically, about that time, the definition of children with special health care needs came out. We just picked it up and used it. So children with any chronic health condition or disability with an increase need for specialized services and care coordination, we left it as broad as we possibly could from birth through 17, and we did have to limit this to those who lived in central Missouri simply because of resource issues for

us. Now, here's the map. So if you can see that, we're right in the center of the state, and our university health care system serves that center corridor all except for the Kansas City side and the St. Louis side. For those of you who aren't familiar, Kansas City is there on the west side and St. Louis is on the east side. (Inaudible) 70 runs right down across the state there, and we are smack up in the middle. And then--eventually, we started out working to nine counties with Boon County, our county, and the nine counties surrounding, and then in the second phase we expanded to 16 counties. So those are the areas that we worked in.

You can see--you're not familiar with it, but really Columbia where the university is, is the largest metropolitan area if you call over 100,000 metropolitan it is by federal definition. And Jefferson City is in Cole County right beneath Boon County. You probably can't see this at the back but the bottom line here it's pretty rural as soon as you get outside that one county. We did take that first year to plan this. Actually we had no idea what we were doing other than we had--we had great goals and we had some knowledge but we were pretty humble about needing to seek great deal of input. So we formed an advisory council that--it consisted of four departments in our school of medicine, pediatrics and physical medicine, family medicine and health management--excuse me--health management and informatics. We enlisted the support of four state departments, health, mental health, social services, and education. So we had all the key players who would need to meet the needs of children with special health care

needs that came through. And then we had family members, a number of them, five or six were on our advisory council, and we also met separately, pretty frequently with families so that they could help drive system changes, and then national consultant Judith Palfrey, and the Pediatric Alliance for Coordinated Care consulted with us, and so did Karl Coley in New Hampshire who had a rural medical home project going on at that time.

So, now I want to stop here and tell you about the program that we actually developed. First of all, I'd like to talk about the primary care team that we developed, then Theresa is going to talk about the intervention process, and then we'll go into the evaluation, and the day that we have gotten over the years on this project. These are people who are really important to me. They've been—they and others have been instrumental, but we've realized in the areas that we were in that we had to form a team in order to create a medical home. And at the core the team was the physician but surrounding the team were people who could really help the physician to make this happen. So the person on the far left, I guess your all far left, is Dr. Tom Silva, who is a general pediatrician who is very influential for the project, and so we had the group of people who were the physicians and the office staff that component, and then of course the child and family were key—the key partners in this effort. And then the family support specialist probably was the element that created the medical home in partnership with the physician. A lot of medical home projects around have actually built up within a practice but what we were hearing from the physicians was that they

didn't have a nurse who could this. So what we created was basically an itinerant nurse, a nurse who went from practice to practice in the region. And actually later in the project, we also added a social worker. So by the end of the project we had two nurses, a social worker and critically also a parent, a hired parent who was a consultant. And so we had the physician in whatever practice they were in the central region, the family supports specialist who went to the practices in order to help with care coordination, and the child and family, and then this hired parent, and this is Dina O'Brian that you see in this picture, and she worked with us for many years on the project, and then this family support specialist that you see down there, and the one on the right here is my person on my left, this is Theresa Petty, and I'm going to let her take over because she was actually implementing this project and tell you what the intervention that we did with families and physicians was like.