

**AMCHP Annual Conference, 2010**

**Moving Ahead Together:**

**Celebrating the Legacy, Shaping the Future of Maternal and Child Health**

**Exploring the Role of Families, Communities,  
and Public Health in Implementing the Medical Home System**

March 6-10, 2010

EILEEN FORLENZA: My name is Eileen Forlenza and I am here from the state of Colorado. I direct our Medical Home Initiative in Colorado and our Medical Home Initiative is housed out of our health department, but I don't come to this work through the typical kind of clinical or public health route, I am a parent of a young woman with special healthcare needs. My daughter, Holly, is actually now 20 years old and so we've been navigating a medical home approach for 20 years now as a family. And so my perspective will be that from a health consumer, family leader role. Had my partner Renee been here, she'd be talking to you about how the provider's perspective intersects.

One of the things that is important as we do this work, all of do this work, is that modeling of partnership. So, when I have an opportunity to present with a physician, and when a physician has an opportunity to present with a family leader, that's a really good strategy. So, you can take that back to your state. When you're looking at ways to model and integrate partnership, doing that together is a really good way to just kind of message and get the word you in a different way.

So you guys are all awesome and strong professionals. I'd really love to know your perspectives here. How many of you are parents of children with special healthcare needs? Great. How many of you are providers that work with families and children on a regular basis? How many of you are with Title V State kind of state systems work? Did I miss any? Any educators, any school health, education? Great. Did I miss any other categories? How many of you are closet singers and you're just here to kind of give your – Oh yeah, I do vocals. But I won't do that today.

So today's session is about the role of families in community public health. But I would really like to expand – this is interactive, so please take a deep breath, relax, this is an interactive time for us. I would be curious if you also wonder if there's a role for other kind of categorical. Oftentimes, what I mean by that is that, when I present, for example to a group of nursing students. They would say, "Wow, I didn't realize I had a role in Medical Home. I thought Medical Home was a primary care provider thing." So, any other thoughts.

Q: Payers.

Payers. Excellent. I'm going to move because I was getting some feedback. Not like people feedback. Payers. And by that I assume you are meaning primarily insurance companies?

Q: Insurance, Medicaid.

Insurance. Yes.

Q: Purchasers. \*\*\*\* insurance with \*\*\*\*.

Okay, purchasers. Employers. What other roles? Yes.

Q: What of the role of the \*\*\*\* Medical Group.

Ah, the role of the BMR. I have found a lot of times that because the medical home approach tends to be ambiguous, whatever we can get our hands around and BMR's is one of those things. Oh yeah, I have a medical, we have electronic health records. Good, that's one piece. And it's definitely a piece of the puzzle. What else have you heard, or you've been curious about what's the role of? Anything? Yes.

Q: Policymakers?

Policy. Excellent. How many of you are familiar with the national group, Patient Centered Primary Care Collaborative, PCPCC? All these acronyms. They talk about the four 'P's'. You've guys seen the four 'P's', they call them – I'm not an

artist, but like the pillars? Anyway, the four pillars of Patients, Providers, Purchasers, and Payers. So, if that's helpful, the four 'P's', that could be more inclusive. We talked about patients more broadly in maternal child health because we talk about families. So, if you think about patients and have a broad perspective. Okay? Anything else? So, keep that in mind because the medical home approach is an inclusive model. And I think it's always helpful in your roles to be inclusive with the folks that you work with because we don't need another initiative in this country that continues the perpetuation of the silos. So, just think – I'm just encouraging you to be inclusive.

So in Colorado, we talk about having a medical home system. And again, I often will encourage the thought process that a medical home is a verb and not a noun. Medical home is a way of delivering healthcare.

Maybe this is going to work, maybe it's not – apologize.

So, the objectives for today is to understand the family perspective within the medical home approach, how cultural competence intersects with that. Explore the difference between family involvement, family advocacy, and family leadership in this context, and the progression of family leadership within the medical home approach because we can talk about medical home at the clinical level, but also medical home from this broader systemic level.

Again, in Colorado, we talked about the medical initiative is housed in our health department, in our Children with Special Healthcare Needs, but we are very involved in the entire concept and we do a lot of work in the adult world as well and we're talking a lot about the healthcare system as a whole, the role of public health is that convener, that it cores essentials of public health around gaps identification, bringing people together for solution orientation. When we passed legislation in 2007, how many of you guys live in a state where you have medical home legislation? Well, not very many. Minnesota, right Linda? Right, and who else? Are you also from Minnesota? Was that it, is that all we have? Wow. And what about you?

Q: Nebraska has a very small pilot program.

A: Okay.

Well, in 2007 in Colorado, we passed a medical home legislation and the key part of this is that we were so passionate about making sure that medical home did not reside only in the place of a primary care. And so this is literally out of the legislation. "If a child's medical home is not a primary medical care provider, if it's not a PCP, the child must have a PCP to ensure that their medical needs are appropriately addressed." So, what does that mean? That means, as a parent with a child with a significant seizure disorder, I would say that my kiddo's consistent source of care is actually her neurologist. And so, but the family

identifying a consistent source of care, we know that with families who have children with hearing loss, they say that their consistent source of care is their audiologist. We could go down the line. That's why including specialists in this medical home approach is a very important piece.

Now, when rubber hits the road and someone wants to be reimbursed for being the medical home, that's when we have to really get clear about what are the roles and what is the context by which someone would get a higher reimbursement rate through Medicaid. So, who asked the question about Medicaid? Yeah, you did.

So, in our state, what we have done in terms of reimbursement is that the providers who go through a, I don't want to go through a certification because that sounds too formal, but in our state, we're using the Medical Home Index. Are you guys familiar with that tool? The families complete the family index and then the Medical Home Index is completed by the whole staff, not just the primary physician. And then when through the Quality Improvement Plan that we're using with a third-party, they will get a higher reimbursement rate for all the Well Child Checks, specifically the EPSDT. And so, right now, that's our form of higher reimbursement.

Denver, not Colorado, but Denver, is participating in the PCMH. The PCPCC pilot, and so we do have all the other insurer's at the table as well.

Q: So was that the acronym for the same \*\*\*\* --

A: PCPCC is Patient Centered Primary Care Collaborative. And PCMH is Patient Centered Medical Home. Yes.

Q: For your approved \*\*\*\* you don't pay a care management fee, or care coordination, you don't pay an additional per member per month \*\*\*\* --

A: Not right now.

Q: And you increased reimbursement is tied to preventive care purpose.

A: Correct.

Q: Across the board, or devoted to children with special needs?

A: Across the board, but they are the children enrolled in Medicaid, right now.

Our state partnership with Medicaid is very strong. And my colleague, Gina Robinson, is presenting today or tomorrow about how our state partnerships have led to some of this. And I'm not an expert on the reimbursement.

So, in terms of the role of Title V, we are really pushing hard the concept of the medical home team. Again understanding that it's a comprehensive and inclusive concept, more than just the PCP.

Increasing the educational opportunities. We do a lot of mentoring and leadership development with families. Some of our family leaders, for example, share the training opportunities at our school of medicine with our nursing associations; we do a lot of that. At our Medical Home Advisory Meetings, which are once a month, and we have people from all over the state that attend either in person, or by phone. We have family and youth leaders at every table, and so we have probing questions at every meeting and so the family members have an opportunity to share perspectives. And the partnerships that have developed just in those monthly meetings is really cool.

The other piece of our legislation that is different is that we wrote legislation that the Medical Home approach is inclusive of physical health, oral health, and mental health. And so yay for the mental health, right? And yay for the oral health. We do not promote the dental home; we don't promote that that is a separate system.

It's really interesting, I was working with a teenager – not a teenager, a young adult who was interning at the health department, and she could not get her hands around this Medical Home thing. And I was explaining to her how it's an

inclusive way of doing business. And she came back after thinking that and she goes, “okay I got it.” So, when she was a teenager, she always had really bad teeth. And as she went through high school she found herself withdrawing socially, never smiled, never went to take pictures with everybody, didn’t join all the things that people do because she felt so awkward. Through that, she developed an eating disorder. Now we’re into mental health and behavioral health. And through that, of course, then her physical health and she said, “Now that I’ve been hanging out with you guys her at the health department, I get it. If only one of those providers would have told the other provider would have told the other provider.” That is exactly right. So, now we have a 24-year-old medical home ambassador in the School of Nursing who we hope is carrying this message forward that if just one of those providers have connected that would have been the ideal way of bringing that together. She’s doing great, by the way.

So you all know the components of the Medical Home, we won’t go into that. The piece that is just exciting is that because we know – a lot of attention nationally has been around access. A lot of it has been around making sure that with full healthcare coverage, that all people will have access to a medical home. We don’t say Medical Home in Colorado without saying Medical Home approach. So, I would just encourage you to – if that resonates for you to think about as you go with your partners, it’s not a place, it’s a way of doing things. It’s a verb. And so, we would say, because it’s family centered, again, what does that look like and that’s where you get into the patient advisory councils and all of that.

And the culturally competent piece, and culturally responsive is not, again just about race and ethnicity, it's about the culture of disabilities, the culture of poverty, all of the social determinates of health that we're beginning to talk about and really think about how your medical home approach, and what your role is in the medial home approach, and how you respond to the different diversity.

So, this is a visual example of having the patient and family in the center. I don't even know if this thing is working, but if it was – oh there we go. So, the patient and family in the center. This is not an inclusive demonstration, but of course, we have primary care, the mental health, oral health and specialty care, all of these typically are in the lives of people with, I wouldn't even say chronic healthcare, but just to consider that if, again a broader perspective. And then outside of that, all of the – we've got summer camps where kids have to have healthcare maintenance while they're out in the community with their recreation.

What's going on at work? This is the employer, the purchasers you talked about. The school nurses, social services, and how all that comes together is a real critical way to understand again that families and patients and consumers have all of this stuff they're trying to coordinate. And so when they walk into a clinical intervention, all of those other things are coming together. So, does that resonate? Does that make sense?

The example that I'd like to share is that my daughter Holly, who is now 20, about three or four years ago was needing to access women's health services. So, here's Holly with significant seizures, over 120 a day, non-verbal, developmentally functions very low, needs full-time care. So, we go to the thought process because in education, her education team said, "Eileen, her monthly menses is getting out of – we just really don't want to deal with this anymore." So, we need to work together on finding a better way. Now, one could say, "Well, they don't have the right to say that." Well, you know what? We're a team and we're honest and they're just saying, this is getting hard. So, I'm not going to pull the rigidity piece of that.

So, we know that we have to go forward with this. I talked to the primary care physician. She says, "You know, I'm just, I don't know how the options will intersect with all the other stuff. She's got adolescent health involved, we've got seizures, we've got all these other things that we need to talk about." So, the gynecologist that we were seeing at the time was advocating for the IUD, or a partial hysterectomy. So, the partial hysterectomy kind of kicked in my grief cycle, because as a mom, I was like, that sounds so dramatic. I don't know if I want to do that. And so, that one was a little bit more difficult.

The neurologist got involved because we needed to really understand how might this impact that particular part of her health condition. And then in developmental disabilities, if you are going to do a hysterectomy on a person with developmental

disabilities, you have to have a Court Order. And thank god for that. Think about where we've come and what a great protective step. So, we've got the primary care physician asking for some support. The neurologist, the gynecologist who is actually our family gynecologist, the Court, the school, all of these people. Guess who's coordinating all of it? And again, not out of – not because the other folks didn't want to, they didn't know how. There wasn't a mechanism in place.

So, this is not, again, a family leader coming to you and saying, "Oh, these people don't care." They do care. I know you guys care. Providers want to do the right thing. We don't have a system in place. Electronic health records are not going to solve this issue. How do we guarantee, how do we assure a coordinated, culturally responsive care?

So, we decided to go with an IUD. Holly cannot do this in a day visit at the clinic. We have to go to the hospital because she can't do that. So, we have to schedule the OR, she has to be fully anesthetized, we have to do all of this. So, the gynecologist doesn't have practicing rights at Children's Hospital. So, Eileen, will you please contact the Adolescent Health Department at Children's Hospital, we happen to have an adolescent gynecologist who specializes in kids. And I'm like, wow, that's really cool. He was very familiar with working with kids that are non-verbal, all of that. But it was still another spoke of the wheel. And it's still me doing this. And I am, I know the system, I speak English, I have friends I can just call. What do we do for families who don't have a clue, by no fault of their own?

They're not non-compliant families. They're not non-compliant patients. It's like we heard in the keynote today. It's the system; the environment that we are expecting families to work in.

So, this testimony, by the way, I gave at the legislature and we got the legislation passed. Because when the legislature said, doesn't this happen already? I mean why do we have to have legislation – like if it was happening, would we be here? It's kind of funny.

Anyway, so Holly had the IUD. All of us worked together. I put together memos and made sure we were all on the email and everything turned out fine. But the point is, one simple – what seemed to be like a simple health intervention, like women's health, was a pretty big deal. And there was a lot put on my shoulders. And granted, I take it; I accept it, but the point being that the system wasn't there.

So, the reality check is who is in charge? And I say that and I know that sounds a little directive, but when it comes to standards and all that we're working in with NCQA standards and all the certifications, there's all this talk about who's getting paid for the care coordination. The truth is that families still continue to be the primary care coordinators. And this is really about partnership. The partnerships are critical, and it has to be intentional. And we have to be able to talk to families in a way that they understand; what's the role? I mean, we had to figure out a way that we have a system, whether it's just a template and a form that says, this

is what you're going to do and this is what I'm going to do. And then we're going to come together. It's really not much different in education with IEP's. So, because we know these partnerships will decrease duplication, increase health outcomes. Right?

So, the value of the consumer input. So, this is part of our talk today is about why, what's the role of families and providers? The role is to establish strong partnerships because families and health consumers can identify the gaps as well as the solutions. And part of your responsibility, and role, and honor, is to begin to identify families who want to give those solutions because I tell you, they're out there. If you put a suggestion box in a clinical waiting room, it will probably get some response.

We know that historically healthcare as an industry doesn't ask for a lot of input. I mean, I have a marketing background and I can tell you whether it was Nike, or a television show, or a new book or a restaurant coming out, they have so much research. What do we do before we do this, and how many Thai restaurants do we have in three square miles before we do this? Healthcare, we just kind of implement stuff and we don't really think about asking the end user. I mean, look at the money that Dell Computers and IBM and what they do to really analyze the end user, the human engineering of how the new mouse pad is going to work. Historically, we don't do that in healthcare. But change is coming, right? The switch.

So, in terms of identifying – this is back to the objective of understanding the difference between family advocacy and family involvement to family leadership. This is a progression model that I just want to share that families initially have got to feel like they have leadership of their situation. So, you don't want to bring families in to a position of partnership at a policy level I'm talking, when they've just received a diagnosis, for example.

So we want to have an awareness of families having a progression of leadership that starts with being a leader of their own situation and their own home. And if what we do promotes excellent leadership in our homes, we've done a good job. If we make really – if we partner with parents to be really good parents and really good moms and really good dads, and really good siblings, that's a really good place to start.

And then families will often decide, they want to be a leader in their community, and that's when they might step up and talk to the principle about how the playground equipment is not adaptable. Or they might decide to put a suggestion in the box at the hospital. Families will then move into a place of leadership in the community.

And then there are families, when given the opportunity will say, I would like to be a leader on behalf of others. I would like to do policy work. I would really like to

chair the Advisory Council at the Children's Hospital. The challenge is that – I call this the outer ring of leadership. It takes intention and progression, and when the stakeholders call, so when the Health Department of Children's Hospital or the school calls and says, "Hey, we have a seat at the table for a parent leader, can you send somebody?" We have got to send an outer ring parent. We cannot send a parent who's right here.

And the challenge is, we as a state, us as state workers and health providers, we don't offer this mechanism. We haven't developed this progression conduit to help families go from the inner ring to the outer ring. But when you send an inner ring parent to an outer ring experience, it's a disaster. It doesn't work for anybody because the parent feel inadequate and feels like, I was set up for failure and the agency says, "You know I've tried this parent engagement stuff and it just doesn't work. This dad comes; he doesn't say anything, he just – he doesn't show up half the time." Well, back to the keynote of this morning, which is a really good primer for this. What was the environment by which we supported that kind of change?

So, my testimony to the legislature that was definitely an outer ring experience. AMCHIP is an outer ring experience and AMCHIP is changing the way we do our family scholars program because of that. So there are changes that are going on. And so, for you, my suggestion is, ask yourself, what can you do to help families go from the inner ring to the outer ring? And if you want some ideas, I can help you with that. And maybe ask yourself, where are you with that? When you think

about family engagement as an agency, are you doing family engagement and family leadership at this level? Are you really helping families with their care plan? Are you helping with that partnership at the clinical level? If so, that's a great thing. And are you encouraging families to get involved at the community level?

When Holly's neurologist told me about a couple of trainings when the \*\*\*\* folks told me about conferences, man I was on it. And the only reason that I have become an outer ring parent is because I had providers like you encouraging me to continue my leadership. And I mean that honestly.

So, in terms of the role of families as partners, understanding that families – I know this can be a sensitive subject, but families with children with special healthcare needs by and large are not asking to be fixed. Families are asking to partner in the wellness of their child. Families are asking to partner in the potential and development of their kiddos and their families. I know that's a hard one to swallow because a lot of the providers I hang out with, they say, "But the families just want me to give them the steps." Yes. It's a partnership. But to get away from a sense of families need to be served, served, served, is a change we're going to have to make together as family leaders and providers. Families want a partner. And I'm not just speaking from my experience, this is from talking with family agencies and family groups across the country.

And so in your role as identifying families as partners at whatever level wherever you are, is to think about what that progression might look like. One of the things that might be a helpful way to articulate this is that families are human capital for your work. Families are human capital for your agency, for your project, they bring -- families and consumers bring a piece that you can't get anywhere else.

The equitable compensation I know comes up a lot, like we don't have money to do this, well you know what? When you treat family partners as content experts, and they're just another form of consultant on your consultation team, that's how we get it through systems. And you have a belief and a value around partnering with families, I would suggest you look at your agency's budget because your budget is your policy statement, and if you really believe in family partnerships, there will be a line in your budget that shows that.

So, recommendations: looking at ways in your state that you can somewhat credential whatever that looks like, consumer leaders, whether it's formalized training, having them be a part of your professional development that you offer your other staff, that's an important piece. One of the messages I want to remind you guys about too is that often times, more times than not, before the families has got that diagnosis of whatever it is that they are now on this journey, they had another life. And we have families who have children with special healthcare needs who are attorneys, who are authors and writers, who are entrepreneurs, who are business owners, who are marketing experts, who are shoe salesmen,

restaurant owners. We've got to get out of this concept that, well the families that we serve in Title V, they don't have the skill set to be a family leader. I'm going to do a myth busting on you right now because that's not true. Families are asking to be engaged. We have to figure out what that looks like.

So, in terms of broad change, these are all faces of true individuals in Colorado who have made an impact on our policy, our health policy. Jillian is a youth that has diabetes and she is part of our training cadre and does trainings with our school nurses on how to manage diabetes in the school. Zarri is an immigrant from South Africa and talks about her challenges of accessing healthcare. Josh is a survivor of a medical error and his mother has changed policy in our state around patient safety laws. This is a Jamaicans immigrant, single dad down in Pueblo, Colorado who has also changed access and some sensitivities around dads in our state. This is Chui Jesus. He wants everybody to know when I do this presentation, he 's getting his degree at the University and he pushed his mother – encouraged his mother and his mom started a non-profit in Colorado called El Group Avida, and it's a support group for Spanish-speaking only families. And they both say, "make sure you say that it was he that encouraged me." But the impact, it goes on and on and on. All of these families. This expanded our newborn screening, this little guy – anyway it just goes on and on.

So all of these faces are real in Colorado, we have changed policy because of the voice of families and how embedded it is in our Title V program.

We were asked not to do handouts, so I know this is hard to follow some of this, but I'm more than happy to put this on your jump drive before you leave, or I think they'll be on the – where'd Michelle go? They'll be on the AMCHP website.

Any comments or questions or thoughts before we move into the next – and when does this session end, do you remember? Eleven-thirty? Eleven Forty-five?

So, any thoughts, questions, comments because we're going to switch into Renee's time and I'm going to do Renee's piece, which I'm less comfortable with because it's not my material. Yes.

Q: This is just a wonderful reflection; I really appreciate you doing this. We have a program called Nurse Family Partnership and essentially partners nurses with women who are pregnant for the first time and women living in poverty, and a small part of what they do, I'm realizing, is teach people how to be activists for themselves, their children, and their family members and understand how this crazy health system works, doesn't work, and how to \*\*\*\* the swamp. So on some days, I realize we've got a connection to this initiative that I haven't ever heard articulated before.

A: Wonderful. Excellent. And that's the power of this kind of opportunity is we can celebrate what we're doing well, we can challenge ourselves of what we can do better. Yes.

Q: Just \*\*\*\*

A: I'm sorry, purchasers. And that's from the other P's. That's from PCPCC, that's not mine. That's – okay.

Q: \*\*\*\*.

A: Yes.

Q: When you passed the legislation of \*\*\*\* did that ensure a pay source for children \*\*\*\*?

A: In a roundabout way. We had – the question was did it ensure a pay source for children. Uninsured, is that what you asked?

Q: Yes

A: Our partner in the legislation is a non-profit run by a physician named Dr. Steve Poole, and Dr. Poole was the head of Pediatrics for our Children's

Hospital, and he started a non-profit called CCHAP, Colorado Children's Health Access Program. It's kind of the 80/20 principle where he realized that 20% of the pediatricians in the state were seeing 80% of the kids and so he wanted to switch that around and so now all, I don't know 620 licensed pediatricians in the state all have an opportunity to have 20% of their practice be Medicaid. So, we're kind of sharing the load. And so Dr. Poole is a part of that credentialing I was saying. So, that's part of that state partnership. Medicaid, the Health Department and Dr. Poole and family voices, the four major entities in our state that are doing that work. So, it's access and it's the payment, and now we're working on all the culturally responsive and all the other pieces. But we know that the first part is that we had to get kids into a primary care physician. Yes.

Q: I mean, is the credentialing actually coming from Title V?

A: No, the credentialing comes out of our state Medicaid office. And I don't want to speak on behalf of Medicaid, so I'm saying what I know, but I may not be – I might not have it all.

Q: I'm going to go back to that 20% -- 20/80 split, are you doing that with dentists as well?

A: We're, oral health is in the loop with us, and so it's in an awareness mode, but I don't know. We don't have the process yet for the oral health like we do the pediatric offices right now.

Q: We are in \*\*\*\* Massachusetts and we had a lawsuit against Medicaid for oral health issues and so we have a new policy whereby dentists can cap the number of Medicaid patients they take. The issue was, that if you took one Medicaid patient, you had to take all of them. And so they didn't want to do that, so they are now allowed to cap and they got a slight pay increase, but it was really the cap that has expanded the pool of the dentists.

Q: \*\*\*\* we had huge frontier areas where kids on Medicaid cannot get \*\*\*\* in the Panhandle. They have to drive to Cheyenne, Wyoming to get a dentist to serve a child in the Panhandle.

A: Yeah, well. That's good news that we're talking about oral health, mental health, and physical health. So, we'll celebrate that. So, yes, Kathy.

Q: My question, what \*\*\*\* very early in your remarks, you were talking about in your case, in Holly's case, naming the neurologist who was the best primary care, what about the really large number of children who have multiple subspecialists and you know, I'm struggling because we're at a place in Michigan where we need to certify our medical homes and they're going to get

significant reimbursement and I'm really struggling with can a subspecialist truly do what needs to be done to coordinate the care of other subspecialists. Should we not be focusing on a primary care \*\*\*\* as the goal.

A: Yeah. Well, back to the legislation says, if the medical home as determined by the family. So, it's that family piece that's really important. In the medical index, some of the national language is "that consistent source of care." So, do families, can they even understand what that means. So who do you call?

I always describe it as forget the word medical, let's talk about home. So, what do you think about home? I kick my shoes off and I walk in the door, it's where people know my name, I know my way around, I'm really comfortable, so for a family, who do you consider your healthcare home, I mean, that's part of that whole territory is it health home, medical home, dental home. So, think about home.

And then it's really about, we have to keep primary care in the middle of this, absolutely. The point is though, when it comes to who is the family identify as who knows them the best, that's as identified by the family, depending on how your payment structures are going to be, that's where your conversation is going to be. So, if the neurologist sees Holly eight times a year and the PCP only sees her once, I don't know, maybe we need to talk about he should have the higher reimbursement. He's not giving her immunizations, he really did not

coordinate her women's health thing, well I was doing that anyway. But yeah, subspecialists do not usurp the role of the PCP. But they can't be minimized in the role of providing a medical approach for the family. Does that help? We can talk details too.

Q: Yeah. Because \*\*\*\* struggle where we have so many children with special needs who are \*\*\*\* on the special needs and they are behind in their immunizations and so, there's also that piece that we're trying to –

A: That's why our legislation said they must ensure that they have a primary care so that those primary health needs are still being maintained. We cannot see immunizations drop; we don't want to see all the health screenings drop, that's not the point. The point is to assert that we are a team and that we've got to stop this siloing affect of saying, well, you work on the heart, I'll work on the head, I'll work on the ears, I'll work on this, and by the way, I might call you when I think about it. We've got to put together a system that it doesn't rest on the shoulders of the families.

So, I'm going to switch to Renee Turchi now, this is her presentation, but she and I talked. This comes from the Institutes for Family Centered Care. Are you guys familiar with that group? Wonderful group to work with. And this is how they define patient and family centered care. And I think all of you in this room already live to that, or otherwise you wouldn't be in this room. So we can celebrate that.

The core element of the medical home as we've already talked about is very consistent with the components of family and patient centered care. As I mentioned, again, I don't have any clinical experience, I am here as a – my background is marketing. But I am a parent of a child with disabilities, so our strategy in Colorado is very intentional that when I became the director of the medical initiative it was to ensure that we never lose that patient centered piece.

My partnership with providers is critical and so when I work with providers in clinical settings, like Children's Hospital or other places, it's the whole cultural brokering thing. They really don't want to talk to me all the time and that's fine, and so I partnered with the physicians in our state and we do this as a team. So, that's a critical piece to understand too.

So, In Pennsylvania, they have a project that's being funded out of Title V dollars run out of their Health Department. Educating practices into community integrated care. Is anybody familiar with this program? Anybody? Because I probably don't know it as well as I should to be doing the presentation, but again, we're wishing Renee well as she is meeting with the President today.

So, in Pennsylvania, the way that they're doing it, and this is probably similar to the Minnesota model with the medical home learning collaborative kind of model. They're participating in the monthly teleconferences, it's a lot around practice

transformation, it's a lot around systems at the clinical level. The providers are receiving information again on optimizing coding and billing and some of the hot topics like transition and cultural responsiveness.

They have a strong component around parent and partners as well. You might also in your Goggle research; Renee Turchi did a whole series in *Exceptional Parent Magazine*. She was featured for about six months on this project. Do you remember that? It's very well-written. They followed a family and so, just in your research if you want to take a look at that.

It's interesting that, again, in Renee's process in their project that they looked at this concept as well. How do you choose a really good parent partner? And again, we're looking at parents not on the inner ring, parents that have a vast ability to look at systems as a whole. Don't want to have families who's kiddo was just newly diagnosed, we know that. The important thing is that when families are in that newly diagnosed phase, they're the ones calling your all the time. So, there's the ones on the top of your head when you're thinking about, wow who are the strong parents in my practice. Who are the parents who are always showing up to our Title V meetings? Well, they're the ones that are searching for resources, that doesn't mean they're ready to do an outer ring experience. It means that they've got good research skills, they're showing readiness for learning, good communication, good listening, it doesn't mean they're ready to – so be clear

about that. Just because they're got the woodpecker thing going on and constantly calling, doesn't mean that they're ready. So, keep that in mind.

This is what's interesting, have any of you seen this report? Yeah. This survey that was done to assess priorities as defined by parents and as defined by the physicians. Isn't that amazing? So, the one thing that was similar was priority number three, which was parent support groups. But what parents said was their number one need was information about community resources and the physicians had it last in terms of what they thought was important. That is telling enough. I mean we don't have to go through any more of these than that one.

What physicians thought were most important was the respite care, which it is important for parents, but this speaks to that, I'm telling you, parents want to partner. Parents want to learn. And parents need a break, absolutely. And that's why they want a break so they can goggle and hang out on the internet and do some research. So, keep that in mind.

That goes back to remember the social determinates of health, remember that it's not always what you think it is in terms of where the family's priorities are. I have developed about six respite programs throughout the state of Colorado and they're all filled and there's a waiting and so on. I'm not saying respite doesn't happen, but what happened in two of the sites, we noticed that parents were hanging out in the parking lot and instead of going off to the movie for the three

hours, they were hanging out. So, now we have featured speakers during the respite time.

So, in terms of how the state of Pennsylvania's medical home project is working, they're engaging of parents doing of some focus groups, the piece that's important here is providing the food and the child care, keeping in mind that, again, back to the keynote this morning, we've got to think about the environment. If you want parents to be able to fully engage and to be present as a consultant and as a content expert, we got to give them the tools that they need. And that is making it easy. Because it's not that they don't want to come.

How many of us have had parent meetings out in rural area and you have two parents show up? So, I can see, I knew I shouldn't have done this. Well, we got to think about what day of the week, well, Wednesday night is probably worship night at the church. Not going to happen. And what were we providing in terms of licensed childcare. Was it childcare that they felt comfortable with? Are we looking at – with kids with special needs, are we looking at peanut allergies and gluten-free meals? I mean, we really got to dig down because if it really matters, we'll ask those questions.

So, this is what Renee's team has been looking at in terms of maintaining and sustaining very similar to what we've already talked about. Diversity is where I see in bullet number three. We've got to make sure we've got diversity in age

and situation. Inviting the staff to the meetings she said was scheduled at different times because they really wanted to make sure that in the first parts of the meetings the families felt totally safe, that they could say, “And your receptionist, she got to go.” And so in some of the meetings, they asked the staff not to attend. And then later they – so they had it scheduled, and it was very organized and making it very safe.

Some of the feedback and some of the impact and the outcomes is that they use a lot of the parent feedback on the development of different care plan models. The bulletin boards is something we talked about too where because families are asking for community resources, if there’s a parent table or a community bulletin board out in the waiting room, a lot of physicians that I work with in Colorado have said, “Well, we don’t want to do that because then we feel liable. Like we have to endorse and check out everything.” No you don’t. All you got to say like they always say. “I do not endorse the products on this table; I’m just offering this as a resource.” So, physicians need to feel comfortable, need to feel like this is truly a community outreach effort and that families really are a part of their quality improvement process.

Their data collection is, they do a survey fairly regularly at least once a year and from that they make their changes. But they are constantly in utilization of data and always surveying families both informally as well as formally.

The other really cool part of their project is they put money toward a website just for the families, and this is a family resource. It's a place that – what she told me too is that from this families have done sub groups, so they have a group of parents who have their own blog around cerebral palsy, the various diagnoses. But this has become the central place. All of this again is funded from their block grant, from Title V. So, this is more about the website.

I think the piece of, if you think about what this helps for families on the website, think about that progression model that's families trying to get a hold of their own situation and then as it grows from these kinds of forums then families learn about community meetings, how they might kick in and get involved and then from there they get involved in other state and policy kind of level work. But it's having a place to get started that's really helpful. Yes.

Q: So, I mean, who gets onto this website?

A: The practices that are participating are over a hundred. So, these are the patients – the families from those practices.

Q: Could you go back to the slide about \*\*\*\* maintaining and sustaining current involvement?

A: That one?

I'm working with our Patients Centered Medical Home Demonstration Project in Denver, and a lot of the practices have simply one simple step, have simply put the bulletin board as one step, and secondly a suggestion box. That something that small they just never did that before and asking for feedback on a regular basis. And then from there they grow their patient advisor boards, or invite families.

With my pediatrician, I was so lucky that we had the same pediatrician for 18 years with Holly, and was able to let them know that in terms of the parent mentoring piece, which is another just step to get started, is that if any parents are needing some resources on how to toilet a 14-year-old who is still in diapers and has needs, they can call me. And we've seen that a lot with families who have kids with autism. Like what are some of the behavior things that work for you. And then we get into the diets. But it's just having that conversation. But a parent – generally you just have to create the space that those conversations feel comfortable. And we can say those kinds of things to each other. Yes.

Q: I'm from Ohio and we don't have a project with a very large primary care network and out of the parent meetings that came around is the pediatric group is also affiliated with family practice, OBGYN, and it's a huge practice in our southeast part of our state. And out of that came a moment when one of the mothers said, "I wish that somebody would pay attention to me as a parent of a

child with special needs when I go to my partner care doctor.” So now in that whole system, they have initiated a question that when they are doing their things, do you have a child with special healthcare need? And it flags them and what that has meant to is a lot of identification of depression, mental health needs, etc., etc. And it’s really transformed the practice, it’s a whole practice. And so I mean, talk about the medical home for children, I really like what you said – it is a journey across all, and that map has, I mean it just really adapted this whole concept of it’s the – she’s a part of our \*\*\*\* now. So, \*\*\*\* medical care, and so I would encourage you when you have enough family groups that you know, we focus so many times on what our children need are and the subspecialists and stuff and we kind of forget our moms and dads. And so the question was not, “Am I a mother?” It’s a, “Are you a parent of –“ And so it is connecting all of these social services and also to help maintain our families intact.

A: That is excellent. Yes, I would like to exclamation point that because one of the stories that I often will share too to drive home that point but also the role of specialists in the medical home approach. When we first started accessing women’s health for Holly, our first step was doing the Depo Provera shot in her little booty, and I just didn’t know that that was going to be difficult for me, but I had a feeling that the very first time that we would go to that appointment that I just felt like I would need some support, so instead of asking my husband to come, which he would have been happy to, I asked a couple of my sisters to come because in my family, when the girls go through their menstrual, and it’s

the – we do this whole dinner and celebration and I felt like that was missing for Holly because it felt more like a different kind of transition.

So, anyway, so we go in for the very first time to get her Depo Provera shot and as she was reaching up and hugging one of my sisters is when the nurse gave her the little poke and we you know, we're like, Oh Holly. And it was fine, and after that, and Holly cried just a little bit, and then when the nurse left, I could not stop crying. I was like, and my sister was there and I was like, this was harder than I thought. Because it wasn't just that – I'm not just a mom of a child with disabilities; I'm a mom of a young woman. And that felt really hard. You know it's like, I can change her diapers and give her her bath and do all of that, and that's what we do as moms, and that's what we do as dads too. I know there are dads in the room. But there's something about being in charge of another woman's body that really hit me. And I cried, and the nurse came back like she would do on a typical appointment and came in and checked on us and she saw us crying and me crying and she said, "You know what, you guys take as long as you need. We have all the time in the world." And that's what I needed to hear. And that was from a specialist. And that's a medical home approach. Family centered, culturally responsive, and aware that this was something that we needed time to process.

So, yes, my husband does a lot of work with dads and so he would appreciate your comment about "are you parent." Because he feels he is overlooked often at

times in this world about parenting a kiddo. So, while I'm here, he's there taking care of Miss Holly.

Any other comments? How are we doing on time? It's 11:15. Yes.

Q: Now, \*\*\*\* faculty can you say something about that?

A: I think that it's a way to include family leaders as part of the faculty team. That promotes this equal partnership and looking for ways that families can help with some of the typical faculty functions and responsibility, for example, in Colorado, I'm working with our school of medicine and writing an online curriculum on this, pretty much a lot of what we just talked about. And so having a family leader as part of the faculty team has been another way that Title V and the USADS and the \*\*\*\* Program has identified family as a discipline and that was another great way that we were able to promote that. Does that help? Okay. Yes.

Q: I'm from the Association of University Center in this \*\*\*\* that supports all the \*\*\*\* programs, so I wanted to put in some \*\*\*\* when you're looking at ways to move some of those parents from that inner circle to that outer circle looking for training and possible ways that they can gain those experiences and take it to the next level, there's a \*\*\*\* training program in 27 – there's 39 programs, and 27 states and in the District of Columbia across the country and they're trained future home care professionals so \*\*\*\* all the disciplines. The \*\*\*\* I work with

diagnosed and treat kids with disabilities but they're all required by the NCH grant to have a paid family member on that grant to participate in the team provided that family perspective and almost all of them also have family trainees. So they come in and their job was, as a trainee, they're disciplined, they're to bring their expertise, they may only have a high school degree, but they are on the same team, at the same table, at the same level as everybody else in the room, nutritionists in training, and social workers in training, and those family trainees just blossom before their eyes and become amazing. I mean, from a community advocate they can spread the word faster than any provider I think that can. And as an association, as a group, there's an article – the introduction of the entire Journal of Family Social Work and family centered care issue coming up shortly. It was written by a group of family, faculty, professional \*\*\*\*, it's a very powerful group. And they are looking for a place to grow those leaders the \*\*\*\* program. I'll just have to find more information in our website, TEC.org. But they're are a fantastic place and resource [inaudible].

A: Excellent. Thank you for sharing that.

I wanted to share with you our hot-off-the-press, still stapled, not finished brochure. And this is a medical home family guide. And what I wanted to point out is that because of the need to communicate very strongly with families, but we also hear the providers say, if you would just use the – you need to hear this

really clearly. So, it's really, we know this is a guide for consumers, but our providers have also given input in terms of wanting it to be very clear.

We're asserting the medical home team approach on the front, but right in to the inner part, we go right into the definition of it's a team approach in addition to the PCP that it's everybody has a role. And then we took the questions from the National Health Survey about when will you know you have a medical home? So, we want to make sure that we're using the same language. Someone helps coordinate your care, those kinds of questions.

And then on the inside, it's kind of the seven components of a medical home, but in layman's terms. Continuous, culturally competent and then we have some statistics in here.

But the back is what I wanted to show you, and that is this partnership with families. This is the way it reads is, "this is what you can do to establish your medical home team." And so this is that call to action that families need to know. Well, what are you expecting of me? And so some of these are, select a health provider that you trust. The data in Colorado showed that the families that are on Medicaid who have a PCP identified, were still seeing four or five different primary care physicians in a single year. So just because they have insurance doesn't mean they know how to use it. So, that was one of the pieces we wanted to do.

Ask for suggestions, make lists of medications, feel free to bring your questions with you, discuss all of your family's health needs to the point about looking at a holistic approach. Contact your health provider before you go to the emergency room decide together if an ER visit is necessary. Always have your insurance card with you. This goes to the children as well. If any of you know Patty Hackett from the Healthy Ready to Work, she's been challenging us to make sure we say, "Kids as young as eight, nine, or 10 years old need to be carrying their insurance cards." Parents say, "Yeah, but they lose them." And it's like, just make another copy and laminate it and stick it in their backpack. It's not that hard. Because the insurance cards no longer have the social security numbers on there, the privacy issues have been mitigated to some extent. So, that's a reminder.

Teaching your children to ask questions.

Q:\*\*\*\* I do this with financial. When they get to be about 10 or 11, I have them sign a consent form and the providers go, "Well you can't" I'm going to respond \*\*\*\*, they need to start learning that I need to ask questions, I'm responsible for my own healthcare, and guess what? We'll [inaudible]

A: Excellent.

Q: I mean, I think it's part of our advocacy that's just like, what do you mean they can't sign this document. It's about them, it's their body.

A: That's excellent.

Q: Yes they are. So, I never \*\*\*\*. I mean \*\*\*\*.

So, I just wanted to share that because there are just small messages that we can start putting out with our families to assert the partnership. Yes –

Q :At the beginning I heard one of the key payers, or a couple of key payers \*\*\*\* or purchasers. I happen to represent a payer, and I encourage and I applaud them for having the foresight and the initiative to bring the payers to the table because you want to partner with them. It's not just if your on Medicaid, I mean, if you're a specialist \*\*\*\* people that have the Medicaid, but it's also a large insured population. So I think it's important to get the payers to understand that it's not just \*\*\*\*, it's not just \*\*\*\*\* it's more than that and if you don't get them to the table as well, I'm not saying they have to \*\*\*\* medical team, but get them to \*\*\*\* what they are doing and get them to understand why this benefits them, it \*\*\*\* to do some type of effective \*\*\*\* providers. Providers, bless their hearts, everybody's \*\*\*\*, but you have to respect them to do this. \*\*\*\* more work. So I think it's something to think about how you can get the payers involved.

A: Absolutely. And the PCPCC story, and are you connected with them at all? They really have come a long way. Anybody familiar with PC – Paul Grundy in Washington? So, to your point. Paul works for IBM, and he's now running PCPCC and so the question came up when the large employers of our country, Verizon, GE, some of the auto makers back in the day, IBM, FedEx, they started asking, why is our workforce so sick? Why do we have so many sick days? Why are our parents going home to take care of their kids all the time, what are you paying for?

So, they started really analyzing their health plans and they realized there was a glaring void in prevention, mental health, oral health, so they did this major significant analysis and started realizing that the purchasers needed to have a little bit more savvy about what exactly are you paying for. So, now you've got workforce development, you've got all the labor folks involved and then it became a bigger issue.

This is not just about healthcare, this is about labor and parenting – it's all the stuff we've been talking about. And so from there is how, because again, Paul Grundy has his career is in IBM and he's their health guy. He's a physician. But he also has a public health background. And so from there, the employers got together with the purchasers, or the payers and that's how a lot of this started. And because Paul has this public health background and he talked about how we really need to get back to primary care who's coordinating this, and that's why

medical home is in – that language is literally in the healthcare reform bill that's going to the Senate right now. So. Yes. That was a way of saying, I agree.

Any other questions. Yeah.

Q: \*\*\*\* and we worked on the medical home project, and so we have – we have parents who walk in when we pay them, to walk in to pediatric offices and also adult side both specialty and regular primary. But it's funded. It was grant money. So, once the grant runs out, what happens is, the pediatrician specialty office, whatever it may be realizes that they don't feel as though \*\*\*\*, and I'm just speculating, but for this parent to stay for this year \*\*\*\*, some will stay and they do pay \*\*\*\* \$5.00 out of the \$20 only to have them \*\*\*\* back. Our struggle is how to continue and how to have them be able to \*\*\*\* medical home and have that key support that \*\*\*\* on the adult side.

A: Thank you so much. Have you guys heard of the Rhode Island model? They do have a – your team is presenting here, I don't know

Q: No. Not at all. It's individual. \*\*\*\*.

A: Oh, yeah, excellent. And I think the key is evaluation, outcomes, being able to solidify that matter in terms of overall business practice and that the care coordination done by the parent helped with – we got to have that business

model on there and look at over all revenue that was impacted by that decrease of duplication of services, ER utilization, right? That's all the stuff you guys are. Yeah. Yeah. So, excellent point.

Q: \*\*\*\* I guess my question – it wasn't just \*\*\*\* it was also like a question of how do you sustain and how to medical professionals understand the importance of this?

A: That's a great question.

Q: I don't know if you can answer that.

A: Well I think the answer is in evaluation when we start looking at the outcomes. Do you want to respond? I think it becomes, I'll give you an example. There's a model going on in Texas. A guy named Brad Thompson, anybody know Brad? So, Brad goes on Friday afternoon when it's children with special healthcare needs day, and he does the clinic and he does all the intake with the families. And Brad is a dad of a 17-18-year-old. He's also a social worker and a pastor in his community. So, he's there on Fridays and does all the intake and does the family centered, really deep care coordination kind of work. And then he hears, "Oh, my kid's being bullied on the playground, he's not eating. Not because he's not eating. He's not eating because he's afraid to go into the cafeteria because these kids are bullying him." He gets all of that stuff. And so before the family

goes in to see the pediatrician then he hands them a kind of a summary. And they take about two or three minutes and do a quick review so that the pediatrician can really work on the health issues and really dive in. And the family also feels like they've been heard and they've been listened to.

So that one practice, from having one parent participating with their practice, they are estimating that they are saving \$68,000 to \$75,000 a year. Because of Brad. Now, Brad, so one would say. So, who's paying Brad's salary? So, because he's only there very part time, it's not that, but also, he's being sponsored by the community, his church, the rotary, some other community groups are paying for Brad to do that. So, there's no cost to the practice and the practice is realizing savings. And so, of course that model is being looked at as a best practice through the AAP and so that's another way. It's all about tracking. It does come down to dollars and people want to know what difference does this make?

Q: And they're saving \$65,000 because the doc has to spend less time getting history?

A: Correct. Yes. And families don't – families are feeling more comfortable and so the visits are more effective when they're there and, yeah. You might check that out. Brad Thompson. He is participating as a family consultant with the AAP Medical Home Project. Yes.

Q: Is there like a place where we can go to, like you suggested the AAP.

[inaudible] something like Brad \*\*\*\*.

A: I'd say the AAP Medical Home site is a good place to start.

Q: But it costs.

A: Yeah. Yeah. And they have a really good family link.

Q: Yeah. And [inaudible] and I heard this guy and then \*\*\*\* it was shown that this was cost savings and doctors think we just did \*\*\*\* part time \*\*\*\* at the beginning there [inaudible]

A: Any provider want to comment to that, I don't really know how to answer that because to me it seems like a best practice model that would work. But any provider wants to comment? No. Sorry, I can't respond to that. I don't know.

I wish Renee was here, maybe she could say something for us.

Well it sounds like we're finished. Thank you for coming.

