

Federal/State Partnership Meeting
Care Coordination and the Medical Home

October 25-27, 2009

MARIE MANN: This session is focused on care coordination in the medical home. I am Marie Mann, and I'm the moderator for this session.

I'm going to go ahead and start because our panelists have to leave immediately when the session ends, and I want to allow us enough time for you to ask questions.

So I want to begin and say welcome. I think it's an exciting time, it's a great meeting. I don't know about you, but I feel tremendously energized by all of the presentations that I've heard over the last day. And though there are many challenges, I believe we have opportunities currently to innovate and make positive changes.

And one of them is around the national discussion or debate directed toward healthcare reform. But it is a genuine opportunity, I think, to really -- for us to think as a country about how we want to address access to high-quality healthcare.

And most of you are familiar with the patient family center medical concept. We're talking about care that is accessible, family patient center, continuous, comprehensive, coordinated, passionate and culturally effectively.

And while this is a concept that originated in the pediatric medical community, it's now endorsed by many as a model of desirable healthcare, not just for children and youth but for adults, and not just for those with chronic conditions but really for all individuals.

We have recognized that a key component to operationalize the medical home concept is care coordination. I think you will agree with me about that, but I also think that many of us in the room will all have different definitions about care coordination. And I think along with that, last year the Commonwealth Fund commissioned Rich Antonelli, Jeannie McAllister and Jill Popp to develop a framework to try to bring those concepts together so that it can harmonize to different thinking about it for pediatric care coordination.

This afternoon we have the privilege to hear from Rich Antonelli about that framework, the characteristics, the functions, assessment, and implementation. Rich Antonelli is the medical director of Children's Hospital Boston Integrated Care Coordination and the associate medical director for Quality of the Physical Physician Organization At Children's and Harvard Medical School. And for the rest of his bio you can look in your meeting book.

We also can't understate the important of families as integral stakeholders in operationalizing effective care coordination in the medical home. And I submit this whole concept of family center care is not just for the pediatric population, but certainly I think we would agree, again, it's for the adult population, for the geriatric population, and

so we're going to hear from Beth Dworetzky, who's the project director of the Massachusetts Family to Family Health Information Center, and the mother of a young adult son with complex health needs. I'm looking forward to hear how she shares with us her expertise.

And, finally, I think we'll hear from Mark Keenan. Mark is a supervising nurse consultant and Connecticut's Title V Children and Youth With Special Healthcare Needs director. He's going to share with us how one state is implementing the medical home concept and finding ways to finance the care coordination piece. And we're certainly looking forward to hearing about that.

So I think each of us is going to spend some time, maybe 15, 20 minutes on each presentation, and then we'll have enough time for some questions afterward. I think it's an opportunity for us to share our various questions and possibly strategies to help implement and spread the medical home concept.

So, again, thank you for being here.

RICHARD ANTONELLI: Good afternoon, everybody. It's really a privilege to be here to be able to focus on care coordination.

Who knows what care coordination is?

(Laughter)

Can anybody tell me the title of a book so that I could read it and learn what it is?

(Laughter)

Who knows what case management is? Who knows what chronic condition management is? How about disease management?

So we're going to discuss some of this today. These are the objectives from my part of the presentation. I actually feel a little awkward because I got nominated to go first, but I almost always like to have the families go first. So please know that I'm good at doing what I'm told, but I do want to acknowledge the fact that much of what I'm going to share today between Patty and Beth and Nora and Barbara Popper, this is for you guys.

So I want to talk about understanding the benefits of care coordination for families throughout all healthcare settings, learn recent developments and the evolution of care coordination that support training and quality improvement, and learn the implications for health system reform of family-centered care coordination.

I have given you all of these slides for your handouts. There will be several slides that I'm going to go over very quickly, but at least for sake of completeness, you have that. This is one of those slides. It's to remind you that when I trained in medical school back

in the early '80's, that green bubble was where flakey people like me thought about, because, you know, for the rest of the medical school class it was all about the red circle. And the challenge for today, and part of the reason why we're insomuch trouble compared to a lot of our international programs, is the linkage between that green and the red needs to be measured and driven so that you can in fact get these informed, activated families with a prepared, proactive practice team.

Is the woman from Colorado who was in the last session here?

UNKNOWN SPEAKER: (Inaudible)

RICHARD ANTONELLI: She's not here? Well, I like her anyway (Laughter), but I just really think she nailed it. Medical home is nothing if it's not based on a team.

So Marie has gone through the so-called seven C's. I can't give a talk without including them. I won't read them. There they are.

I will call your attention, though, this is not just about docs, but the nurse practitioner community has also endorsed the family and patient-centered medical home.

So what do we know about the medical home? In fact, it does eliminate disparate in healthcare. Racial and ethnic differences in getting medical care are eliminated when adults have medical homes. This is some seminal work of the Commonwealth Fund.

But is medical home enough? It demands system redesign. So as the primary care system in the U.S. is currently configured, it can't get the job done. We need redesign for the financing, quality, the regulatory environment has to change, and policy support. By itself, medical home will fail. Integrated care is essential.

What are the elements of an integrated healthcare system? Does anybody -- and this is not rhetorical -- feel that they are either patients or employees of an integrated healthcare system?

So let's talk about integrated care. It is fundamentally family centered. Families help define the agenda. Shared quality goals with clinical outcomes, reduced variation in service delivery. You know, those bullets sound like any kind of a successful business model, and yet it's so alien to the healthcare approach.

Shared fiscal accountability across all stakeholders. Patient receives the right care at the right time in the right place, not an over-, an under-, or a mis-utilization of resources. And everything that I do for the last couple of years is based on that equation, the value proposition. Quality is not enough. What's the cost? Cost is not enough. What's the value?

One of the reasons why it's a privilege to be at a place like the MCH meeting and actually to deal with this community is because we're not just talking about medical

issues here, we're also talking about housing mental health, et cetera. So it's all aspects of what make us humans.

The steep principles from the Institute of Medicine help provide the foundation for the medical home approach. And health information technology is not sufficient.

I'm going to share this slide with you. This is the first group outside of Children's Hospital Boston to see the infrastructure that we're proposing for our work. I'll call your attention to the left that have slide, the medical home, typically provided by primary care docs, but for children and youth with certain types of conditions the PCP, so-called, could be a subspecialist. And at that level of the medical home there's accessibility. Care coordination is a measurable inseparable part of the functionality in that medical home, tracking and registry function and linkage to community-based organizations -- those are the red and the green balloons that I showed you -- with an electronic infrastructure.

On the right side are all of our inpatient and our ambulatory subspecialty settings. The integrated care infrastructure is everything in the middle. It is not esoteric. Clinic communications. Everything can be based on a care plan. A care plan is a transaction for a healthcare interaction. The family owns the care plan. The family contributes to the creation of the care plan.

Structured communications between PCPs and subspecialists and the families are included to help define what the agendas are there. Optimum models of care, including collaborative care models. Sometimes you don't have to deliver services in exam room by laying hands on a patient. Sometimes that's the most expensive and least efficient way of doing it. But when you live in a fee-for-service environment, those are the types of widgets that you create.

We're putting together models now which are based on -- forgive me for being really simplistic, but it's almost a telemedicine kind of a model. If I have a child who has a seizure disorder, why can't I pick up the phone, speak to the neurologist, put together a care plan that includes their ability to give me input, and have that neurologist receive reimbursement for that? It saves time for the family, it utilizes resources very efficiently, and because it's captured in the care plan, it's auditable.

So we're working on these so-called collaborative care models. That is the disruptive piece of the framework for us. Interoperability? Yeah, I fantasize about that. Do we need it? Sure. Is it going to slow us down? Absolutely not.

Utilization management and being accountable for our outcomes. Now, some of you have seen this slide before. I think it's still pretty relevant, and I want to acknowledge Bonnie and Marie and the MCHB for funding this study.

After about six years in a row of having my practice be threatened to be closed down because, quote, I attracted too many complicated kids to my primary care setting, I decided that there's no other profession that would put up with that kind of -- fill in the blank (Laughter) and I decided to do this study.

And what we did is we measured activities in a busy primary care setting with about a 40 percent rate of children with special healthcare needs by the federal definition, and we said what are the activities that we do that make families get the care that they need that aren't getting reimbursed? And that's the key. These are non-reimbursable activity.

Well, interestingly, only two-thirds of the activities had something to do with a medical or clinical management decision. Referral management. Finding the right subspecialist in the right town with the right health plan. Social services, including housing and food and clothing and educational, mental health. People have dinged me in meetings before because I've talked about mental health as a carve out. I did it on purpose. It deserves to be identified for that sort of insular entity that the system has configured it to be. So if anybody wants to throw a glass at me, you can. But it's more important to recognize that it's there and it gets done and it doesn't get reimbursed.

So this was a wake-up call. The National Study of Care Coordination, we looked at half a dozen practices around the country, different models, and we said what happens as a result of an activity for which that practice did not get reimbursed? Did anything occur? Did anything get prevented?

So in fact about a third of 3800 encounters prevented something. 58 percent of the time, because of a telephone-based, non-reimbursable interaction, the child and family did not need to come into the office. A quarter of the time an emergency department visit was prevented. And 10 percent of the time a subspecialist visit was avoided. 62 percent of nurse care coordination encounters prevented something, while a third of the physician encounters did.

This is the first study of its kind, and it may be still the only study of its kind to show non-revenue-generating office nurses drive the most system-level cost savings. And those would be avoidance of emergency department and office visits.

Name a single successful business model where the better your performance, the least likely you are to collect revenue and the least likely you are to have your customers coming to you to give you revenue. Right? You can't name a single one. Shame on us.

So I'm not going to go through this entire tool, but suffice it to say that the National Committee on Quality Assurance has come up with a so-called patient -- and I want to thank Marie -- family-centered medical home model, standard three, case care management, which is their version of care vision. This is really ground-breaking acknowledgment of the need to have non-physician-staffed advantaged patient care, conducting care management, including care plans. It took a year of advocacy, and it's in there.

Now, this tool is weak -- and the NCQA will admit it themselves -- in two areas. One, it's weak for care coordination in general. And, two, it's weak in capturing and measuring family professional partnerships.

We are currently working with the NCQA to rectify those two areas. We had to get this out quickly in order to inform the pending Medicare demos.

Deep breath.

Who are critical partners? Title V. Funding support programs for children and youth with special needs to facilitate the development of these community-based coordinated systems of care.

It's time for -- you know, I would look at Title V to help raise awareness in the policy world of the connectivity between that medical bubble and the community bubble. It's very challenging for the healthcare providers to make those connections, because in fact we even have financial incentives that prevent us from doing that.

In Boston we have a community asthma initiative that has amazing results of keeping kids out of the emergency department for asthma and out of the inpatient setting for asthma. We're saving about \$1,800 per child per year with our community asthma program.

So what's the problem? The problem is it's all done with non-reimbursable care coordination, and we're losing about \$2,400 to save \$1,800.

So right now one of my major problems as a medical director, totally, totally dedicated to the notion of family-centered care and optimizing outcomes, is you've got your public health silo over here and your medical silo over here, and so I would look to the role of Title V to help us make those connections. If I'm saving money in the public sector but costing money in the medical sector and vice-versa, we need a rebalance.

And think about it. The bottom line should be what's best for the kids and the families.

We need to influence system integration. The notion of integrated care, integrated systems, yes, they do exist in the U.S., and we call them Geisinger, we call them Kaiser, Group Health is probably another one, Advocate Health -- I can count them on one hand, but I can tell you that there are very few entities that I can look to that are pediatric integrated care organizations.

The broad focus on children and youth with special healthcare needs is critical. We know that these are children at risk. In my opinion, the at-risk component hits me in the face every time I go to clinic. But it doesn't show up in slates [phonetic] data. And people keep focusing on the 12.7 or the 13.2 or the 14.1 or whatever they want to do,

but remember, and especially for those families that are living in poverty, that's not going to show up. But we know that that is a significant determinant of health outcomes.

And, finally, a bully pulpit. I'm too shy to use that, but I can ask you guys to do that for me, please.

(Laughter)

So logical but not necessarily traditional teammates to make this happen. The public health community, including dental and mental health community, public and private payers. I have commercial and public payers asking me for advice to redesign systems of care. It's a surreal time right now. We have to seize this opportunity.

Purchasers. I cannot acknowledge enough of the value of what the patient-centered primary care collaborative has meant to me. I have gone from a flake to an expert witness all of a sudden, and it's because the purchasers have basically stood up, and I'm going to quote Paul Grundy, who's the -- what is he the chairman or the director? He's the boss of the PCPCC: We're tired of paying for crap. He actually said that in an open forum at the National Quality Forum meeting.

And what he meant by that is if IBM could choose vendors for their silicon chips, they're not going to choose the worst possible products. They're going to choose the best and what gives them the best value.

They are constrained, however, when purchasing healthcare for their employees. So thank God for the PCPCC, because they have actually added oomph to the movement of family-centered care and the medical home transformation.

Education. And family to family support. That last bullet is more than just customer satisfaction. It's a completely -- except for the case of maybe the few of you in the room that I've acknowledged -- an almost completely untapped resource in terms of its ability for clinicians to use.

I'm also humbled and thrilled that the family to family is the only piece that -- well, maybe not the only piece -- but the only committee that reported that out intact was the Baucus bill. And whoever in the room pulled that off, I want your autograph.

So where can we look for advocacy and examples? So multiple states have introduced legislation in the last couple of years and active legislation around medical home, but how do we develop these integrated care systems? The way to think about it is you can put all kinds of developmental resources at the level of a primary care setting. And as you spread throughout that practice, we'll call that a mini horizontal integration, across practices, maybe, but now it's getting weak into the community, even weaker.

How about going vertically? And I don't mean to imply that one is more important than the other, but in a different sector. So how are we going to integrate that primary care setting with the subspecialty setting?

So these are the ways we're going to drive these integrated care systems. How do we develop support and measured care coordination? I would submit to you that it's the care coordination in fact that is the driver for linking this system up.

So what are some of the components of the work that we did for the Commonwealth Fund? This was a multi-disciplinary group that we convened that included families, included purchasers and payers, included the nursing community, social work, both pediatric and geriatric and we came up with this definition.

It's a patient and family-centered assessment-driven team-based activity designed to meet the needs of children and youth while enhancing the care-giving capabilities of the families. You can see how that resonates with the geriatric community.

Care coordination addresses interrelated medical, social, developmental, behavioral, educational and financial needs in order to achieve optimal health and wellness outcomes. It has team all over it.

So what are some of the components of care coordination? Family-centered and community-based, proactive, providing planned comprehensive care. Pro-active.

Remember that. Think about how much care coordination gets done in the system now that is reactive. It's because you've had that heart attack, it's because you have or are about to get a knee replacement, it's because you are depressed. So it's proactive.

Promoting the development of self-management skills.

For those of you that are -- I'm assuming most of you have policy connections. This is not a dependency model, it's an empowerment model.

Facilitate and cross-organizational linkages and relationships. These are the functions that we've proposed in our framework.

Providing separate visits and care coordination interactions. At the National Quality Forum I was able to convince them that we shouldn't just be measuring visits for care coordination, that often times a non-visit may provide the most cost-efficient and most family-centered approach to doing care coordination.

So start thinking in your respective system designs of care coordination encounters and think how you would measure and structure them.

Managing continuous communications across the system. Analyzing assessments.

Standard assessments of needs. And that needs assessments survey should be informed by your family and youth partners.

Coaching patients and families, integrating critical care information, et cetera.

So you think that is challenging. What about the cohort that's stuck between two worlds? And these are the youth with special healthcare needs.

It's very, very challenging within the system. So now we're going to sort of exponentially bump up the number of permutations. What are some of these realities?

40 percent can't identify who their PCP is. 20 percent consider their pediatric specialist to be their regular physician. And primary health conditions often aren't met.

How can we address this disparate? Care coordination. Removing administrative barriers which currently limit co-management between pediatric and adult primary and subspecialty care. We can drive transition with care coordination if we can get over those bumps.

What about the other transition? Where can the system generate ROI? So for anybody in this city that thinks that pediatrics is high on the priority, it ain't. It's all about ROI and it's all about Medicare. But that's okay. As pediatricians, we're happy to take the crumbs. Just let us flick a few once in a while.

(Laughter)

Why is hospital discharge such a driver of cost? So I call your attention to this 20 percent unplanned readmissions in the Medicare population. More often than not, that is not because the patient had a regression in their clinical status. It's because the community systems fell apart.

If we could ameliorate those 20 percent unplanned readmissions, that's about \$500 million.

What about transition and care from inpatient to outpatient? I call your attention to my friend and colleague Eric Coleman, who right now is the only National Quality Forum tool for care coordination that has endorsed three simple questions and have a high correlation of predicting unplanned readmission. Caretransitions.org.

What can we do now to transform the system? Care planning utilization with the family and youth having input into developing that care plan, it can be the template for any encounter. And this is how we will support team-based care. This becomes the roadmap. My mantra is in an integrated care system, the family knows at any moment in time who's responsible for what. And if that accountability changes, there's a mechanism to inform them.

A standardized tool for a needs assessment so that the families know what's in scope for their conversations. People have a hard time understanding what I mean by a care plan. This is it. What's the problem? What's the activity that needs to happen for it to be

addressed? Who's going to do it? What's the timeframe? What's the expected outcome? And what's the follow up?

It's not rocket science. But it's pretty disruptive when it comes to traditional medical approach.

And access to what? Remember, face-to-face E&M visits is not necessarily the answer. Co-management collaborative care models. And I am almost done.

Aligning centers and goals. How do we finance this? Financing is really cool, you guys. Think about that. The only new money, the only new revenue stream in healthcare reform will go into the medical home and will go to -- and part of that will be dedicated to care coordination.

So I come back to my original question. What is care coordination and how are you going to train people?

So these are the next steps.

Building on the framework in the Commonwealth Fund. We're going to develop a multi-disciplinary family-centered care coordination curriculum. Pilot the curriculum, evaluate its efficacy. Link the care coordination to certain outcomes.

We'll study things like who is the best target audience? Is it the nurses? Is it a whole new cohort of allied health professionals called care coordinators? Is it the families? Is it the physicians?

I sort of plant those seeds to be provocative so you can be thinking about that, but developing a curriculum and looking at how it can change the culture.

Building a care coordination framework into state and federal legislation and regulatory language. Continue collaborations with the MCQA and National Quality Forum.

And just an hour ago I got an email from the NQF. There is a whole set of proposed measures and practices that went up today. So please go to the NQF website and query this. I think that they close the public comment period in only about two, two and a half weeks. It is a, if I say so myself, a remarkable opportunity to transform the landscape, but you need to get your friends and colleagues to go there quickly.

Thank you very much.

(Applause)

BETH DWORETZKY: Thank you, Rich.

My name is Beth Dworetzky. I'm the project director for the Massachusetts Family to Family Health Information Center, which is a project at the Federation for Children With Special Needs, and a grant from the Maternal and Child Health Bureau funds the work of our Family to Family Health Center.

And, like you, I have -- that's my day job, but I also have many other responsibilities, and one of them is I consider myself a partner in care coordination for Zachary's plan, and I'm his mom. He's a young adult with some complex health needs, and I'm going to share the family perspective and some of our families' experiences with care coordination in the medical home and provide some suggestions for ways to bring families on board as potential partners in the coordination of care for their children with special health needs.

And the universal truth of the Rolling Stones.

(Laughter)

In a perfect world, we wouldn't need care coordination and parent advocacy or leadership skills because no child would ever get sick or hurt or be born with special health needs, and everyone would get what they want and what they need without having to work for it.

But we don't live in a perfect world, and Rich and Mark are working to sort of create that perfect medical home world that provides a symphony of medical services and community supports for families raising children and youth with special health needs so that they'll have what they need. And Rich has laid out a great vision for what care coordination can look like, and Mark is going to talk about how we move that system of care coordination forward in Connecticut.

However, for most families, including my own, care coordination hasn't always struck the right chord. If we're lucky, we get the right note or two, but many of us are still hoping and waiting to enjoy an entire concert of care. And until that time come, I suggest that parents take center stage, make their own music, and orchestrate their children's care coordination to ensure that they receive needed health services and community supports, reduce duplication of services and unnecessary testing, help control costs, ensure patient safety so that our kids feel supported not only that their medical needs are met, but they also feel supported in their community.

So this is -- when my son was born, he spent most of the first year in and out of the hospital. Mostly in. And one single hospitalization lasted 134 days from October of one year to March of the next. And I'm mentioning this because once January rolled around, there's a whole new deductible and catastrophic limit to be met, and I will say we maxed that out. We continue to max that out every year.

But despite all of the people in and out of his hospital room on a daily basis, no one ever said, you know, is your health plan meeting most of your needs? He would have been eligible for SSI because of the long hospitalization. In Massachusetts, once the 30 days rolls over and it looks like it's going to continue, they waive your family income and they just look -- and because SSI comes with a Medicaid wrap, it would have helped significantly with all of our deductibles and out-of-pocket costs until we did meet the catastrophic limit.

So I mention this because this is a photo of Zachary taken during an Early Intervention visit. And because the person who used to coordinate Part C services in Massachusetts in this room, I'll say Cape and Islands ER rocks (Laughter), where we got Early Intervention Services.

And again, this is an example that despite numerous discharge claiming visits, no one ever told me about Early Intervention. I found out about it completely by accident because I was reading a publication that I received from the American Heart Association where people kind of listed their kids congenital heart defect and the services that they were receiving, and all of them said receives EI or received EI. And I'm like what is this EI?

And I went to our pediatrician who kind of poo-poo'd my concerns about my son's development. So I looked in the phone book, found a new pediatrician, and also found a number for Early Intervention.

And, you know, Zachary may have been okay without Early Intervention. I clearly would not have been okay (Laughter). It was transformative for me. It really helped open my eyes to what I was going to need to do and the role that I was going to need to take in his care, but it also was sort of like that stepping stone for opportunities that when you saw things happening in a system that needed change, it was actually a place that said come help us figure it out.

Whoops. There we go. Let me just check something.

Okay. So anyway, Zachary was born in 1990, and it wouldn't be until 1998 when the American Academy of Pediatrics invited me to be part of a conference planning committee for the Every Child Deserves a Medical Home Training Conference in western Mass that I would like really hear and learn and begin to understand the concept of a medical home.

Because in all honesty, I don't know –

MARK KEENAN: -- services. I wanted to draw some interesting comparisons and contrasts with MCO chronic disease management and I wanted to give some hope for collaboration and moving things forward at this particular time.

In Connecticut, as in a lot of states, care coordination on the pediatric side has been driven by special healthcare needs programs. And the first jump to services -- there's really a jump to indirect services from direct services. And from 2002 to 2005, services were indirectly provided, but they were still centralized through two large tertiary care centers: Yale and Connecticut Children's Hospital.

By 2005 approximately 900 children and youth with special healthcare needs were receiving care coordination services. So in a little state like Connecticut, we basically drew a Mason-Dixon Line, and we could still only reach about 900 children.

One of the issues was a cultural one, and that was, as we're talking about, the Maternal Child Health Bureau's definition of children with special healthcare needs. These folks were only seeing those folks with the most complex needs.

Slates [phonetic] was telling us the last round was 133,000. So 900, not so good. So in response to some outside influence, the Office of the Child Advocate and some other stakeholders, we established or our commission established a medical home advisory council.

And it was -- if you look at the mission statement here, it's MCH language, which makes it a really good mission. Forty members plus seven or eight parent advocates out there the entire time. We have in the last couple of months -- we're representing Connecticut kids as self-advocates. There is a young gentleman who is a self-advocate who actually

has complex special care needs himself who represents a mentorship program. There are nine different state agencies represented. There are payers, there are those tertiary hospitals that I mentioned, and providers, different stakeholders.

We had the good fortune of having Richard Antonelli as our co-chair for a couple of years, which didn't hurt.

So between 2005 and 2007 services were regionalized. They were moved to five special needs support centers. Some of them were successful, some of them were not as successful as the others. But at least in Connecticut now instead of drawing a Mason-Dixon-Line, you kind of chop the state up into five pieces here. And it's a small state.

In 2007, 2820 children with special healthcare needs got care coordination services. So we're getting a little better. And basically -- and also I want to mention that we're talking about essentially flat funding here.

2007 to 2009 was a real change in the services. During this generation of services we contracted to five area care coordination networks who provided co-located or embedded care coordination services in pediatric primary care settings. Child Health and Development Institute and the Family Support Network partnered to implement provider family outreach and education statewide. Child Development Infoline of the United Way served as a statewide single point of entry and referral. Connecticut

Lifespan Respite Coalition served as a statewide respite and extended service administrator.

This was a huge difference in really getting to the community-based. So what you have is embedded care coordinators who are actually in the medical practices. You also have some overlying enabling services that are supporting this system.

And the jump in numbers was phenomenal. In a single year, 6782 received services. And as I said, essentially flat funded. So within a few years we went from 900 to this number. And it's interesting, when you look at the complexity, we had 900 of the most medically complex. You've got, I don't know, like 1500 or so of the medically complex still there. So those kids are still there.

There are more than 100 different primary diagnoses. When you look at the breakdown, it supports our broad definition of special healthcare needs. Forty percent are split evenly between autism, asthma, ADHD. There are 32 medical homes, which include a variety of different settings; community health centers, hospital clinics, pediatric practices, family practices.

Really, depending on the existing infrastructure in the different areas of the state is what we looked at. We gave folks some flexibility in responding to our request for proposals to really maximize what that part of the state looked like. In a small state like Connecticut, there is a lot of difference in infrastructure. I had some experience working

in regulatory services so I got to travel around the different state to see this firsthand. If you were in the eastern part of the state, there's some very rural areas. If you were in Stamford, you were almost in New York City. So we've got a real contrast in the kind of structure that is there.

Care coordination services include a lot of different things here. The scope of services is very broad indeed. It includes assessment, care planning, home visits, family advocacy, linkage to specialists, linkage to community-based resources, coordination of health financing resources, coordination with school-based services, chronic disease case management, and family education.

And I wanted to compare and contrast a little bit with chronic disease case management and Medicaid case management, so that's why this is highlighted.

We look at this as a piece of broader care coordination approach. So it gets circa 2002-ish, and I like to show this because this, with those two large centers, are the towns that had at least one child with special healthcare needs that received services.

And then I like to do this to show you.

[Laughter]

Our state legislature loves that. Particularly the folks who are looking for their town. The only thing is we still have Lyme, Connecticut, ironically, as a -- doesn't have a child with special healthcare needs. I always love that line in Madagascar: What's in Connecticut? Lyme's Disease.

[Laughter]

Here's an overview of our current structure. You've got five networks in the center there that divide up the state. As you can see, you've got social service organizations and you've got hospital-based systems here.

Connecticut Children's Medical Center is back as our contractor. Newly back. This year's contract. You've got [Inaudible] on there. But you can see that these folks have different organizational structures as well. Some of them are hospital-based, some of them are social service-based, but they all are composed of interdisciplinary teams. And I want to emphasize that also.

So ideally they have on staff a registered nurse, they have a social worker, they have all of that so they can maximize the expertise that they need to within their team. They're also connected to the teams in the primary care practices. So they participate in the team meetings and the discussions and everything that happens.

Now, we talk about care coordination versus case management. And it funny, I make the rounds at our Medicaid MCOs, and I show them all of this, and I pointed out, just like this, that care coordination includes chronic disease management, that it's a piece. And I thought I was going to be in for an argument, but all acknowledged it immediately, that they agreed that this is actually the case, that chronic disease and case management is specific. It's not as broad a based approach as this.

So care coordination, it's got all that stuff. Medical and non-medical domains, coordination of health financing resources, family education. And case management is resource utilization, benefits, Medicaid, MCO, chronic disease, case management is part of that. And in Connecticut we've got something called HUSKY H-U-S-K-Y, which is our Medicaid children's insurance -- MCO plan. HUSKY is Health for Insured Kids and Youth, which the letters don't quite match up to that, but it's a marketing genius because they have Yukon huskies in this state, you know.

[Laughter]

So it was a really great marketing piece for them. And it's interesting, when you look at what the Department of Social Services having those MCOs, who they contract to do the HUSKY piece, the kind of data they collect to look at compared to the kind of data we collect to look at. It's an interesting contrast. I call it quality measures here. It's the data that we're looking at.

So in our system on the care coordination side, we're looking at comprehensive care plans, family involvement and care planning, family satisfaction, screening for special healthcare needs, successful linkages to resources, some EPSDT components, and then our systems, goals and objectives are a no brainer, right? They're the MCH performance measures.

In case management, it's different things. It's an analysis of performance improvement projects, it's mandatory reporting of data on case management for high-risk pregnancy, asthma, diabetes, cardiac, neurological, NICU babies. You can read all these things.

And the systems, goals, and objectives are different too. It's to improve access to care and services, preventative and primary care, improved postpartum care, improved provider network, and to reduce inappropriate ER use and admissions.

And, you know, what I like to leave folks with is that they are complementary to each other. This is all beneficial to children, this is all beneficial to families. And going forward in the future, we really need to work together to make sure that the pieces are covered.

And then I throw this up here for you. So the MCOs, you've got three of them who contract to do the HUSKY. It's Aetna, AmeriChoice and Health Network of Connecticut. Now, a little over a year ago we had a changeover in these MCOs, so this is actually a good time to start working with them right in the beginning.

And here are some rates that DSS, our Medicaid agency has forwarded to me. Now, the case management piece is not separated out in here at all. And they don't really have a schedule that they're being reimbursed for that. It's basically included as part of the contract.

Now, pharmacy, dental and behavioral health are carved out. The pharmacy is managed through the Medicaid agency directly. Dental and behavioral health are through an ASO, so it's important to work with those folks also so that we don't end up with a truly fragmented system instead of one that is really cohesive.

So there's the PMPM. Now, you've got HUSKY A, which is -- it's up to 185 percent of the federal poverty level. There's also a HUSKY B that goes higher, and there's a sliding scale buy-in for that piece of it. And there's also a HUSKY B Plus, a waiver program for those with higher needs.

Now, to make it more confusing, you've got something called primary care case management that our Medicaid agency is also piloting. It was established at the direction of the Medicaid managed care council -- and I've got their website here if you want to look at it, all the different data on this -- as a fourth option to these MCOs.

And the reason that this was put out as a fourth option was to keep them competitive for future contracts and negotiations so that it would keep them honest, it would keep things competitive. Sounds like something else, right?

[Laughter]

So let me point out what the problems were.

It's 750 per member per month. It goes directly to participating providers to do care coordination services in addition to primary and preventive services which would be done on a fee-for-service basis. Okay?

They also would be required to provide case management at a minimum for diabetes, asthma, depression and childhood obesity.

Now, the pilot was just in two counties, which doesn't equate to our regional system at all, but in two counties, 59 providers enrolled. Unfortunately only 211 consumers after about six months were enrolled in this. So what's the problem? There are about 300,000 plus in HUSKY A.

The problem was, according to the providers, that no additional funds or time is given to them for the promotion of this. The HUSKY pieces well established, probably because of that marketing bit. Everybody knows what it is. This no one has ever heard of before.

The MCO contracts also prohibit direct competition. In other words, you cannot directly recruit from those who are already a member of one of these MCOs. Okay? And that, no doubt, came in during contract negotiation during this next round. Okay?

And it's not a default option, so if your family says I don't care, just put me in something, they cannot put them in this one. It's got to go, by default, into one of those other three.

So, you know -- yes.

[Laughter]

So at this point, you know, what we are doing is we would like it to work because it helps the system. Anything you've got that can put another dime into the system at this point probably helps us. But the buy-in here to me, from the providers, also is coming off, like, a cultural issue here. Because we're actually asking the providers to go out and hire a care coordinator to do these services themselves.

And as I said, our care coordination network, basically it's a couple of different ways. They either hire care coordinators who are embedded in practices or they travel between practices within that region. So they spend time here and there. They all kind of do the same strategy. The real larger places, they'll have their full-time person.

The third option for that is they can directly subcontract with the provider to hire their own. That's not the popular one, I can tell you that. It's the toughest sell. I think we've got four out of the 32 medical homes that operate that way just because they really don't know who to hire or what to do. They certainly don't have the time to do this.

So there is collaboration and potential in this. And we are collaborating with both the PCCM providers and the MCO case managers to avoid duplication of services, maximize limited resources, increase care coordination capacity in the practices, develop strategies for reimbursement of care coordination services, and to serve more children and youth with special healthcare needs and their families.

The MCOs are on board as soon as you say duplication of services. We're going to avoid that. They want to work with you immediately.

At this point we are trying to work through this. But we know that for this to really be sustainable it needs to be linked to reimbursement. And all of these folks agree on the same thing, which is the next step in that is to have this care coordination curriculum, to have a legitimate standard and some kind of a certification process for this.

We've got some support. The Medical Home Advisory Council has worked through what we are establishing as core competencies. What are the core competencies of a care coordinator. Which is the bottom row.

The A.J. Pappanikou Center for Excellence in Developmental Disabilities, which is our USAID in the state, is going to be working with us in the next couple of years to do an online curriculum -- so we'll be looking for other curriculums to partner with them -- and going forward a couple of years down the road would like to incorporate some of that training into actual curriculum at Yukon classes for both the registered nurses and the social work program.

So that is really our next step in really for -- to getting some sustainability in the next level of moving forward to having things financed.

I'm done.

[Applause]

MARIE MANN: So I want to thank all our panelists. And I'm sure those of you in the room will have some questions or you want to share some comments. Please feel free.

UNKNOWN SPEAKER: I have a question about the curriculum. So is there some effort at looking like at developing one national curriculum since we're [Inaudible] and then having to go through the process of trying to get them into some sort of [Inaudible]?

MARK KEENAN: Would you like to answer that?

UNKNOWN SPEAKER: How about you?

MARK KEENAN: Can everybody hear -- can you repeat the question?

So the question is, is there an effort or a desire to have a single curriculum as opposed to having 51 different curriculum, kind of like Medicaid programs, right?

So I can tell you there's a strong desire. The work with the Commonwealth Fund, if you remember nothing else about it, remember that it was multidisciplinary and on purpose. Because if you look at different entities right now, the American Academy of Pediatrics has a definition of care coordination and the American College of Physicians has sort of a definition of care coordination that looks a lot like chronic condition management. So we're trying very hard to get all of these entities together.

The hope, in fact, is that there would be -- there's reason the whole process and the framework can't be uniform. What the actual content looks like should actually be informed by the needs of the community and the families in that community. So care coordination in inner city Hartford is going to look different than it would look in Beverly Hills other than it would look in Dubuque, Iowa. So that's the notion here is that we would help to link the care coordination framework from the Commonwealth Fund that may report a [Inaudible] citation to actual care coordination with sort of tracks. A family track, a social service track, nurse and clinical track and communications across the

system of care, and then we'd provide the sort of techniques and structure, methodology, for doing a local needs assessment.

Does that --

UNKNOWN PERSON: I mean, I'm in New Hampshire, and I have the privilege of working with Jim McAllister [Inaudible] so I'm thrilled to talk about [Inaudible] something recreated in different places. There's a lot of -- it takes so much [Inaudible].

MARK KEENAN: Yeah.

UNKNOWN PERSON: [Inaudible].

MARK KEENAN: They absolutely are. In fact, that was the reason that Jeannie and I configured that foundation document and so that the next step actually be -- but there's going to be the two pieces. There will be the standard component of the curriculum, the how to do it, and then the other pieces going to be, you know, rural versus urban and taking into account the cultural competency factors. Okay?

MARIE MANN: Are there other questions?

UNKNOWN SPEAKER: I just have one related to that question for Rich and for Marie. There are some that expect that reimbursement is going to be linked to the NCQA

recognition [Inaudible] and I think if that does turn out to be the case down the road, this notion of incorporating the standards for care coordination within that framework is going to be critical. You may not be able to capture all of care coordination, but I think from everything you've said today, that it's going to have to be broader than case management, but it's going to have to be standard enough so that -- there are lots of issues with NCQA recognition programs, but if it does turn out to be the platform for reimbursement, I think it's going to be important to make sure it represented.

And my question is what's your take on whether the NCQA recognition program is going to ultimately become the platform for reimbursement for lots of things, including care coordination?

MARK KEENAN: Yeah, it's -- so the question is is what is my opinion, and my fellow panelists should weigh in as well, about the likelihood that the current NCQA, so-called PCMH tool, will become the standard.

So this is July I was in the room with a woman who's the vice-president of NCQA, and somebody else made the statement that the NCQA is the gold standard for assessing PCMH. And she was the person who was most disturbed of everybody there. Especially the pediatric community said wait a minute, what about partnership and care coordination and all that? And thank good Dr. Sarah Scholey [phonetic] said, no, that was never its intention.

The intention was to have some sort of a measurable benchmark, if you will, to establish improvement. I think that there's great credibility in the NCQA. It's an external entity as opposed to, say, American Academy of Pediatrics. I'd love to be able to say, yeah, we'll measure ourselves, but that may not hold sway. And I'm not even sure that it's necessarily worth fighting that.

The NCQA has indicated great interest in cooperating with the pediatric and family medicine and nurse practitioner communities to be able to move this forward.

So my strategy right now is to do everything we can on the pediatric family centered [Inaudible], including calling it the FCMH as opposed to the PCMH, and then the reality is that there's a great hazard of having all care coordination dollars come through fee for service in the medical home. And the hazard is that we'll incentivize the development of an a boutique system of care. So people will be able to cut their panels in half or by some significant number and be able to take all that revenue and basically make up further losses on Medicaid.

And I'm not saying that to disparage the pediatric community. I'm saying it because there's a market principle that will operate here.

So in answer to your question, I think that the NCQA tool is the best thing we've got. The NQF policies and procedures that are up for public comment will be a huge opportunity to move the ball forward. And I think the jury is really out. I, for one -- if you

look at the data that we generated on our study, paying doctors to be care coordinators is not a good utilization of our resources. We're not trained for it, and if you take me off the front lines of seeing patients, there's significant opportunity cost, and we all know that there aren't enough primary care providers of any ilk to meet demand right now.

Thanks.

UNKNOWN SPEAKER: Diane?

MARIE MANN: Diane?

UNKNOWN SPEAKER: Hi. I'm with Champions For Inclusive Community, and I really appreciated hearing all the different perceptions on medical home.

The one aspect that I'd like us to have some more dialogue on, and I think particularly given this focus on [Inaudible] in that community needs perspective is what about coordinating all the other folks that are doing care coordination? And I'm thinking -- you know, back, I think you kind of tapped on that to some extent in terms of families often having multiple care coordinators, and who does that care coordination often can differ depending along that life course. And so that's one aspect.

And then the other one is that sense of the role of the medical home in more service system policy level integration at a community level. We focus a lot on family level care coordination. What's the role, for example, on inner-agency councils [Inaudible].

MARIE MANN: There's two parts to the question. So I'm going to ask if, Beth, you wanted to try to address the first part, which has to address an expanding, this concept of care coordination, particularly since the meeting focus has been talking about life course. And so --

UNKNOWN SPEAKER: [Inaudible].

MARIE MANN: Well, I think if you can just give your own personal perspective.

BETH DWORETZKY: We've never had a care coordinator. I wouldn't even know how to address that.

Mike Fraser, during the lunchtime plenary or whatever, had said hope is not a strategy. For families, hope is a strategy. I mean, you can always hope -- you know, like there's a great line from one of those National Lampoon family vacation things. With each day there is new hope, which, you know, you just -- I honestly think that if families don't figure out a way to sort of, like, track all the information, our kids will fall through the cracks.

And I'll give you a great -- I'll give you an example. My son now has a endocrinology team, a vascular team, a surgical team, and not just a cardiologist; we see an electrophysiologist, so like a subspecialty subspecialty.

When an endocrinologist makes the change in the med, she doesn't tell the cardiologist. I tell the cardiologist. The cardiologist was out on his own medical leave. So I spoke to someone else on the team and I said the change in the dose makes me unaccountable. She's bumped it up too much, because every endocrinologist that we've ever dealt with -- and we've dealt with a lot -- assumes that the family or the child is non-compliant in taking the meds, and that's why it didn't work. Because if they're not seeing a kid for diabetes or something like that, they have no idea what they're doing.

And that sounds terrible. I apologize if there are any endocrinologists in the audience. But that's the bottom line. It always comes down to are you sure your kid is taking the med?

My kid is truly an example of better living through chemistry. If he was non-compliant with the meds, he wouldn't be functioning the way he's functioning.

She bumped the dose up a lot. I called the cardiology team and I said I'm -- he has a bunch of heart rhythm problems -- I said, I'm really uncomfortable with this dose, the change in the medication. And they kind of said, well, it really takes an awful lot to get toxic on that and cause arrhythmias.

Wouldn't you know it, my kid developed a new arrhythmia problem. Now, I'm not saying this single cause was the change in the medication, but when the cardiologist -- and this has been kind of recent, and the cardiologist, you know -- it's been really a long struggle. It's been going on for, like, six months now. And he started to, like, look at all the meds, and he said, Why is this so high? And I said, Endocrinology made a change. I spoke to the team. They said don't worry about it. And he says, You know what? I'm going to make an executive decision and I'm going to start worrying about it.

I mean, in a way I feel like I fell down on my job because all along I'd been saying -- but, like, who else is going to do that? Really, who else is going to do that? You know?

So I don't know. Are there families that are receiving multiple case management services from multiple agencies? How do you get them to talk to each other? I truly think that if the parent -- like I truly do run around like a chicken with my head cut off trying to make sure that everybody's talking about the same thing, and there are still gaps in the system. I have no idea.

UNKNOWN SPEAKER: Can I just ask you a follow-up question? [Inaudible] you work with who would identify themselves as --

BETH DWORETZKY: No. No, I do not.

UNKNOWN SPEAKER: So you don't have anyone who --

BETH DWORETZKY: I am. I mean -- no, I really do not think that there is.

UNKNOWN SPEAKER: And, Beth, your health plan does not step in and give you a nurse coordinator to --

BETH DWORETZKY: I will say at that occasionally -- that's kind of a long, funny story which I won't tell because there's not enough time. But that has happened once. Okay? And, truly, every time I, like, bargain with somebody to get something paid for, like over and above, they change the contact person.

MARK KEENAN: So, Diane, I think at that you've asked a critical question in terms of linking the red balloon and the green balloon on the chronic care model. And the notion here is that it isn't just tweaking the way the system is currently configured. I mean, this is a transformational approach to what is case management, what is care coordination.

So the fact that this young man is 21 -- 19 years old and has all of these issues and there isn't an identified care coordinator. So we have could carve out what care coordination is. It needs to be anchored to a structured, endorsed, validated and accepted and measurable set of functions. And the curriculum will begin to inform policymakers what they can measure.

So I envision care coordination as becoming essentially like an allied health field, and there will be -- and a family-driven, family-informed standardized assessment that includes mental health needs, case management needs. Tell us who all your case managers are. Right now nobody in the system is collecting that information in a structured way that then informs what the care plan looks like.

So that's the reason to bring this message to the Title V committee, because I think this stakeholder is the piece that's missing from the clinical side. But the care plan, the care plan is the driver. That's the roadmap to make this happen. But there's lots more that we have to do.

You sort of tilt your head when I mentioned the clinical piece. Did I --

UNKNOWN SPEAKER: I was just thinking about the care plan. And you still hear other providers in a community like the [Inaudible] Early Intervention program saying we've got a coordinated care plan --

MARK KEENAN: Exactly.

UNKNOWN SPEAKER: -- social worker [Inaudible] Early Head Start Program, then well all have a coordinated care program.

MARK KEENAN: And there's --

UNKNOWN SPEAKER: [Inaudible] the one spot of time of time we actually had a care coordinator working with us on our IFSP for [Inaudible].

MARK KEENAN: Yes.

UNKNOWN SPEAKER: [Inaudible] I'm just saying for a two-year span of time we did have somebody working, I will say if it's just an EI and some community piece itself, there was -- like the whole medical piece was not part of that equation. But in all honesty, is that their job? I don't know.

MARIE MANN: I think you bring up the point that when we're talking about care coordination and talking about medical home, we're not just talking about medical model, that we're really talking about coordinating and linking the medical with the non-medical services. And so in fact the health system needs to be communicating with the education system.

And so when we talk about transitioning, it's not just vertical transition from pediatric to better healthcare, we're also talking about transitioning across settings. And, you know, whether it's from child care into our inpatient-outpatient child care to educate the school.

So, I mean, this is the long-term vision. But we have to begin with a vision. And so it's linking those various systems. And if we have some uniformity into what is the exact information we need to be sharing among the systems.

So we have our work really set out. But on the other hand, you know, as Mike Fraser said, we need to be thinking and don't be boxed in by what's currently in place.

UNKNOWN SPEAKER: Up in Oregon we have ten communities that are running what are called community connections network teams.

MARIE MANN: Let's hear about Oregon.

UNKNOWN SPEAKER: Well, I'm offering this as one possibility as a response to who's coordinating the coordinators. We have -- in Oregon through our Children With Special Healthcare Needs Program there are ten currently trimmed down from as high as 15 communities in which we in a sense spawn multidisciplinary teams that come together around a child that's been referred into that team, and where the phrase has been with complex unresolved issues, and that is where the coordination of the coordinators and the various entities that are involved with that child happen.

And so depending on the child and the family and the issues they present, we may have EI or Department of Justice or Mental Health or the educational specialist and whoever. So we can have -- the highest number I've seen in some of those team meetings, and

I'm only looking at the data from my director's point of view -- might have 15 people around the table.

The family is always present with the child. A family leader is always present, a family liaison, that is there to assure the voice of the family. And the family leaves -- I mean, there may be an individual within that group that will own the coordination and followup with the family -- this is my bias -- I, as a parent, still feel it is the family who is coordinating this care.

I think it's a mythology to believe or to want any one family to hand that off. But it's an empowered family and it's an informed network of people, and it's working very effectively in those communities right now.

So I think that's one possible function.

MARIE MANN: I just want to add one point we haven't which will spent a lot of time talking about, but there is a tool that can help us move toward the better coordination and communication. And that's the use of health information technology. I think there are lots of barriers, but on the other hand, I would encourage us at the state level to -- there's a lot of money going out to the states right now to better use health information technology. And it behooves us to really learn more about what's happening at the state level, to participate at the discussions, in those discussions, so that you can be integrate

into part of whatever, you know -- the money that trickles down so that you can, you know, at least have some input into how that money is spent.

And I think sometimes people don't recognize the significance of what you can accomplish at your level. Because I think that bidirectional flow information of information between public health and clinical domains are critical, and yet most times people don't understand how all of you -- Title V is a critical interface.

So I would encourage all of us to go back to our states and really find out more and participate in that. So you have a question?

UNKNOWN SPEAKER: My question actually was to --

BETH DWORETZKY: Do you want to introduce yourself?

UNKNOWN SPEAKER: I'm Shelly Meredith from Kentucky, the Children With Special Healthcare Needs Program, and we actually -- we have always had direct care in our clinics, and we have care coordinators [Inaudible] who are supposed to be coordinating care on a single plan in connection with Social Services. So my question is about bringing in all of those other components and inviting them to retain them, because I think often our [Inaudible] coordinators, they here with the family and they're trying to make connections, but they don't know what's available in the Social Service areas and they don't know who to even call in the Department of Justice, let alone get them to the

meetings. I just wonder when your strategies were for making those connections and having them a phone call away.

MARIE MANN: I'll repeat. The question is to find out who did the care coordinators become -- gain the information about the available resources.

UNKNOWN SPEAKER: [Inaudible].

MARIE MANN: And across the different settings. So when like a foster care -- a child in foster care coming in and out of the justice system. Okay.

UNKNOWN SPEAKER: We have within the team somebody who plays the role of the coordinator of the team. Not a care coordinator but a coordinator of the team who is supported to send the [Inaudible] needed to pull all of the records and [Inaudible] and beginning linking them with the different providers involved with that child and family [Inaudible]. And then the physicians that we [Inaudible] we give them some money to come to the table, they will perform a meeting with the family and an examination of the child, and all of that comes to the table together with the family. It can take some time, and some of our teams are moving into more active care coordination by bringing the families back a second time for follow-up.

I forget to mention that our care coordination in our state happens through our local public health department getting on the phone to Connecticut to find out more about

your medical model. So if that child has been brought to the attention of or referred into our [Inaudible] program, then that public health nurse will be there as well and often an expanded examination. So it's a search and rescue operation, part of that coordinator of the team and records.

MARIE MANN: We only have time -- I think there's one more comment or question.

UNKNOWN SPEAKER: How do children get referred. There's efforts in marketing the team to the community broadly, and anyone can refer. A family can self-refer, a physician can refer, a neighbor can refer. It's really open. We have a lot of school referrals coming in. There's been quite a bit of effort into taking the program and advertising or marketing it to all of the major places where kids are, you know, making people aware of it. And these are teams that were originated probably 15 years ago out of a [Inaudible] grant that were intended and cited in what are considered the more rural communities of Oregon. So it is a rural-based network.

MARIE MANN: And you fund this with just Title V --

UNKNOWN SPEAKER: [Inaudible] Title V dollars. And, I mean, I think what -- we haven't done the measure. One of the measures that I'd like to do this year is what these dollars are leveraging. We are investing no more than \$8,000 per community plus the money for physician time. And these providers and coordinators come to the table. And we don't have a measure of what that dollar value is.

And people have asked me, well, why do people do that? Well, these are very small communities, and communities where people know one another. They see these kids in the grocery store [Inaudible] but people are connected and they want to see them happy.

MARIE MANN: I'm sorry, I have to end the session because our panelists have to go catch a plane. But I really thank you for your attention and for being here. Thank you.

[Applause]