

## **Title V, Social Security Act:**

### **Honoring Our Past, Celebrating Our Future**

**October 20, 2010, Washington Hilton Hotel, Washington, D.C.**

### **Modeling Partnership: Working Together to Advance the Medical Home Concept**

MERLE MCPHERSON: I'm going to start while they're setting up because we're running a tiny bit late but it is a terrific pleasure for me to be here at the 75th anniversary and hello to all my old and new friends. I want to take a couple of minutes to make sure one understands the success story in Title V. That act, passed in 1935, included a discreet component that provided funds to locate, diagnose and treat crippled children that you heard us talk about this morning. That program had a very proud history but when I entered the federal government in the late 1970s, it was obvious the great changes that occurred by medical changes, strong, early intervention and special Ed programs and Medicaid and all the social programs of the 1960s. Title V needed to change that component. And so a decade began of national intense building led by the surgeon general and based on partnerships at the local, national and international levels with voluntary organizations, with employers, providers and a very strong family leadership tied to that, I know many of you were part of that and remember all of that work we did to come to some consensus of that and I want to acknowledge the department of pediatrics for their help in this time. We took out crippled children and we replaced it with health care needs and we added a new legislature requirement that maternal and child health that facilitates the development of community based system for care. We knew all of the words. Together we replaced a model that was based merely on a crippled defect to a new family centered model home based in communities for all children and on the understanding and science that children must be served in the context of the families and the communities in which we live. These community systems are measured by six performance measures. And are grounded, truly grounded with universal access for all children for quality health care. We have an outstanding panel who will address modeling of the true partnerships and while I describe the Title V success, I really am describing a success of hundreds of other organizations because we are all in this

together. They were tell their story, broaden it from children to adults and share their perspective. Aim going to make some very short introductions. Paul Grundy is the president of the patient center primary collaborative and adjunct professor at the university of Utah. He has championed the patient centered medical law. Richard Antonelli is director of the integrated care children's hospital in Boston. He was in general practice when I first knew him and then from 1987 to 2000, he went full time and really practiced medical home. He's one of the Pioneers to our grant and study care coordination costs and finally, we have family clean --. W.C. is currently the director of family information and education family connection of South Carolina. He's pastored in Columbia for 12 years and he really supports a passion to foster healthy family formation and has worked in multiple areas besides children with special health care needs. I'm going to turn it over to them for the next 25 minutes or so to tell you what is a medical home.

PAUL GRUNDY: Thank you very much. It's a pleasure to be with you here today. Maxine waters said that you really can't build a nation without a foundation of maternal and child health and I'm here today to tell you that you cannot build maternal child health, you can't deal with the foundation for that until you build an integrated and coordinated system and the one that we're focusing on today that is now the standard of care in the European union is known as the patient centered medical home that comes out of the pediatric literature as far as back as 1967. I had the privilege of visiting a rather large academic medical center in Connecticut as the person who buys care for I.B.M.628,000 lives. As I drove to that academic medical center, there was a giant sign on the freeway and it said, we do the best heart surgery in the state. I looked out at those C.E.O.'s and C.F.O., in fact, all of the oh's were there because we're a large buyer in the community and I said, you know, we're not going to put another job in this community. It isn't going to happen. That's not the sign we want to see. We want to see a sign that says we get integration of care. We get the fact that the social determinants of health and the health care delivery system have to be integrated. We get it so well, in fact, that in this community, because care is comprehensive, I understand grated and coordinated, your employees see one less necessity to have heart surgery. And then and only then -- by the way, you know, we do the best heart surgery. And so we really have to take the 2.7 trillion dollar flow of money and begin to integrate it more meaningfully into the social determinants for health if we're going to change the next slide. The next slide is our enemy. That - - this is a report that came out this week, in fact, in health affairs and if you look at that top red square there, we are -- we are now the sickest. We are now the least -- the least in the ability to have a health care industry, a sick care industry drive transformation. What that means for me, and what this slide says is that my employees who are age 45 and for the next 15 years have a higher death rate than any other developed nation on the face of the earth which is a good way of looking at the value proposition that the sick care industry delivers us. It has failed us. It has been failing us for the last 40 years. You know,

we've got to turn that around. It's a great report. You should read it. It's our enemy. We can't as a buyer of care, as a corporation sustain the ability to provide care for our employees without addressing the fact that sick care. So this slides shows us we're 19 out of 19 developed economies. When I was born in 1951, the United States happened to be the life expectancy here happened to be the fourth of all nations in the world. This year we're number 67. So we really have to begin to look at some of the fundamental foundational issues of transforming the health care, sick care delivery system and integrating it into wellness. So what I.B.M. does and other companies are doing are beginning to look at that. We actually pay \$150 to our family members to help them work with their kids to keep them from being obese, right? We want that kind of message of health and wellness integrated into the sick care system. We wanted to at least amplify our message of health. So next slide. So this is the issue for us. We have the best care in the world. We have the best livers, hearts and it's kind of like the Olympics a few times ago. We had the best basketball players in the world. They got whooped. Remember that? I can get a really good amputation for my diabetic. I just can't get the care that prevents it. We don't coordinate. We don't integrate, we don't talk to each other. We don't have a plan. We don't have a master plan. We don't have a master builder, you know? We don't have a project manager. I mean, there are places in the United States where -- and this particular history was one of them, where it cost me \$170,000 for the last six months of life for one of those people between, you know, those 15 years between 40 and 60, right? Or the 20s and 40s. You know, we have other places where it cost \$16,000, \$17,000 for the same six months. And the mortality in those places are lower, significantly lower. When I look at that, what I find is a robust system of prevention and primary care in that community. When I look at the community, it's \$177,000. What do I find? I find five partialists all doing a part, nobody talking to each other and by the way, no adult supervision, right? So I have places literally in the United States, a couple of communities in Florida where we're lucky enough to get care called Kaiser where I actually see one third less need for my employees to have heart surgery and I.B.M. does data. We look at the data. You know, it starts, it all starts with good prenatal care. It all starts with basic, you know, it's not rocket scientists. It's b1p, it's cholesterol, it's prenatal care. It's wellness and childhood, right? It's getting our folks to start exercising in preschool. And in places where they do that, we really see transformation. The Spanish, if you remember that last slide, they went from being 19th to fourth in 10 years. They moved their system to something called family and community medicine and every Spaniard has a way of integrating their sick care into their health care and I went out and we had the minister of health from Spain that came and talked to us a couple of years ago and then I went and visited them. There were three names on a light board in a clinic that I visited and I said, you know, what are those three names? And the young lady who was in charge of that clinic who was a graduate of the family community medicine program and was running -- understood population medicine, she said those are the three kids that haven't gotten their

immunizations. We've emailed them, mailed them and phoned them and haven't come and we're sending a car out to get them but we're not going to let anybody die of diphtheria in this region on our watch. That's population management. So at the base of all of this, at the fundamental foundational base of a health care system that's going to work, begin about thinking of turning it around and I -- integrating it. We need a team willing to deliver integrated, coordinated care. That's because that's where the phone is, right? So it has to start with a trusting relationship, you know, in an environment in which the sick care system begins to amplify a system of health. That's what I want to buy. So a bunch of us, large employers about four years ago, 47 of the 100 got together in a room and said we want a change of covenant. We don't want to buy what you're selling anymore. We want to buy integrated, coordinated care. We said give us a set of principles upon which you can all agree are a set of principles that would be foundational for that. They came back with a joint principles of the patient center medical home. It's really, really powerful. It's really, really powerful because it's the first time we've had an agreement that comes out of 30 or 40 years of history of this in the pediatric literature. It has a strong foundation and a strong root and we the buyers have agreed to begin to change how we pay. That's now beginning to happen all over the country. There are at least 37 plans now that are paying differently for care that's coordinated. This is the kind of care we're talking about. We're talking care that has superb access, care that's coordinated, integrated, much more centered on the patients' needs. There's a registry. What's happening in society now is that for the first time, we have data. Data that's going to become actionable information at the point of care. Where do you have to make that data end up? It's got to end up somewhere and it's got to be in the patient center medical home. It's got to be at a place where accountability can occur. For the guys that are going to deliver the care, for the healers in our society, it's going to do to their mind what x-ray has done to their vision. It's going to do for me, the buyer of care to my ability to understand accountability, right? What the M.R.I. has done for me to understand what's going on with a knee joint. It's going to profoundly impact what happened. So places that have done this, Denmark, for example, which is the furthest along in this, they've got from 155 hospitals in the last 15 years to 21. Why? Because most care is done in the ambulatory environment that should be done in an ambulatory environment, right? We're seeing this happen in the United States in pockets and it's very, very exciting. It's going to be an exciting time to live and I think with that, I need to wrap this up. And move on. Thank you very much.

RICHARD ANTONELLI: Aloha. It's pretty cool that merle is sitting here. Did you ever think it would come to this? I'm mindful that it may have even been this hotel and it certainly was this city, remember healthy people 2010 express? A bunch of us showed up. How many hands? There was a lot of hope in that room, wasn't there? We had a sense of what the model needed to look like. It was a profound

movement with maternal and child health. Forgive me for what I'm about to say but for the most part, the adult community didn't understand it at all. The pcpc wasn't born yet but there was a lot of hope because it was the right thing to do. In addition, I also happened to have a lot more hair back then. Here we go. Don't forget. Who am I aiming this lacer at? It did start with this MCH. That's my notion of celebration but now I have a notion that is intended to sober this audience, okay? Medical homes won't be successful, especially if I can't get this slide to advance. If their integration -- how about if I just put my finger up and we'll do it that way. Go back, please. Go back. Go back. Integration of care across the continuum from the patient and family perspective. There are systems that are system sent Rick. We need to keep the patient and family at the center. What does this look like? I'm about to show you the blueprint for the delivery system to support patients and family centered integrated care at children's center in Boston. It's focused on the patient and family experience it's a medical home model. Typically a pcpc but for especially academic medical centers, subspecialists can provide the medical home experience as long as they meet and provide all of the elements of accessibility, care, coordination, et cetera. How do we link that with the inpatient and the ambulatory subspecialty unit? we have patients and families helping us to create these so structured communications between pcpc's and subspecialists. The use of a care plan that follows the patient through the continuum of care, designing new ways of delivering care for particular diagnoses, conditions that we're going to talk a little bit about but I would like to call your attention to the notion of a collaborative care model. The locus of that responsibility is totally transparent to the family and the family was part of designing it. Interoperability, the exchange of information is absolutely critical for safety and quality, utilizing resources appropriately and because I'm now a medical director, a lot has to do with accountability around quality and outcomes in financing. We could build the best system in the world but if it doesn't deliver value to the purchasers and for all of us in the audience that are taxpayers, the system isn't going to work. So we're not just building on hope. We're now building on urgency. One of the biggest problems that I have in Boston is our community initiative. It's patient identified as being at risk due to admission to the in-patient unit for asthma or emergency department utilization. Nurse, case management model includes a home visit where asthma information is given and we're given a hpa vacuum. There's a community education component for families about asthma. Advocacy at the local regional level and I can't thank my colleagues enough. Why do I call this a dilemma? Check this out. The asthma initiative has decreased emergency department --for children in the Boston urban core by 60% in two years and the effect is continuous. We've reduced inpatient admissions 80% and it's a sustained event. Reduced missed days from school, missed days from work. Why is this a medical director's dilemma? Financing. Has anybody in the room successfully written a prescription for a vacuum cleaner? The good news is that we actually have the payers that recognize that wait a minute. Maybe there's a different way of providing care. It was a treat for me to see Jim Roosevelt

on this morning's program because we're working collaboratively with our payers to develop the new systems of care. Policy changes are absolutely essential to make this happen. Now, I want to talk about equity. And it's a broad sense of equity and health care reform. Everybody hears about aco's. I can spell an aco, I can give you about 432 different variations on what an aco could be but even the people that are credited with sort of developing, if you will, basically say it's a 10. Vulnerable populations could be at increased risk as systems evolve because the acos that are coming out right now strong focus on adult care and children generally could become vulnerable. Lack of pediatric quality measures. Legislation introduced the notion of a significant commitment of resources for developing quality measures for children. Strong emphasis in the aco pilots on inpatient and adult care. Remember very strong emphasis on Medicare and determinants of health. The first presentations this morning have been so inspiring for me. It is about the lighted course and the social determinants are really important for us to think about. This is the article that show us the environment in which children and families function. My guess is that everybody in the room understands this. But one of the problems with creating accountable outcomes around health is if we're stuck in the medical silo, that carves out and I'm using that term very carefully, that carves out mental health. That prevents linkage to education, access to literacy, et cetera. I think that MCH needs to focus on health and outcomes, not just utilization of medical resources for Medicare recipients. In 10 years, God willing, I hope to be a Medicare recipient. Those actually avoid many of the opportunities that MCH has been focusing on, life courses and prevention. So I want to share the five d's and we'll go through these quickly because I want to hand over the podium to my colleague. This is the academic pediatrician association policy statement around implications and I'm proud of this. Notice it doesn't say pcmh. It says fcma. Guess what f stands for? This is suitable for young ears to hear. The family centered medical home. It is patient centered, yes, but we have to take into account that broader circle of support. What are the five d's? [Applause] thank you. Development, just keep clicking through these, please. Evaluating must include functional and developmental outcome. Care coordination change over time, right? Adolescents need different care coordination than newborns. There are defend aens issues, defining what the circle of support is and the shift from acute to chronic conditions, looking at the -- looking at care coordination as a deliverable action set of activities. Go ahead. Demographic patterns are different on a percentage basis more children live in poverty than adults in this country. financing is critical. Care coordination needs to be funded as a set of deliverables that isn't just on the backs of the primary care providers. That's why we can't get enough people to go into primary care. I want to tell you that the family is at the center of the team. In my opinion, the family is always the principal care coordinator for that child. It's up to the system to decide what kind of adjunctive support they need. We have lots more to do. Thank you. [Applause]

WILFRIED C. (W.C.) HOECKE: Why in the world do they put a preacher last? That's going to be scary, okay? My goal today is just to give you a families perspective on what MCH t p has done. We'll just advance with our finger. How is that, boss? How do you spell medical home? For me as a parent, I want to give you a little insight into what's going on inside of us and what was my experience personally as a dad. 15 years ago my wife and I are expecting our first born, pastoring a church. I get the 911 page. Baby is on the way. I'm so excited about having my first born. How many parents do I have in the room? Stick the hand up. We need aerobicks so if you're not a parent, put your hand up anyway. As parents we have these visions and dreams for our kids and I wanted an educator. My wife and I have education degrees. They're going to grow up and change the world. You know, that's what my hope was. I'm all fired up. I get to the hospital. My mid wife has allowed me to deliver all three of my kids so I'm not just cutting the cord. I am actually delivering this kid. I pull this kid out and I look at him and he sticks his tongue out at me. He looks weird. The mid wife said wrap the baby up and bring him to the mama. She said I'm not done yet. She said wrap the baby up and bring him to the mama. I'm like, what is going on? She laid Carl in his arms and it's my strong decision that Carl has down syndrome. W.C., it's time for you to pray. Now, that's cultural competence, okay? And I laid hands on Carl and I dedicated him and do you know what? It was so beautiful. I can't remember a word of what I said, okay? But I'll never forget what Marie prayed. She said God, W.C. has been asking for a teacher. And you decided to give him one. It's just that W.C. is going to be the student. Most prophetic word I've ever heard. Having a child with special needs and receiving that diagnosis changed the whole world view of how I was going to work with that child. Stepped out the door and she says, listen. I need to get a subspecialist. He's great but not practicing at this hospital. It takes a couple of days to get him. Can I make a phone call? I said please go for it. She said doctor gold, do you have a minute? In walked Dr. Gold. And in 10 minutes he gave me a definition of what down syndrome was. I still use it today working with families. Awesome, clear, concise information on how to work with my child. We had a little murmur. We might have a heart issue. I still have the napkin where he drew the heart chamber and what we needed to do. And I was really freaking out bays I know they wanted to take this kid away for all of these tests. It looks like I'm running for political office. He says, you know, we're going to run a bunch of tests and I'm like, well, I don't want to be away from him. He turns to the hospital staff and he said this father will never be more than an arm's length away from this child during the test. He was there for Carl's first meal. I was there for his echo. That's family centered care, okay? I'm in there with Carl and we get back to the doctor and he says, you know, I typically don't share this with all families. If you're a physician, right this down or if you're a practitioner. He said I typically don't share this with families but I think you're ready for this. What does that do for me as a parent and as a dad? Ready for this? He says, you know, in the next two weeks, people are going to say some really stupid things to you and you're not going to know what to do

and everything inside of it -- it's like at a funeral and you say something really dumb. People push away from you. This wonderful Jewish physician says you need to apply grace. Now, to an evangelical pastor, that means something. I have to give these people grace. Next two weeks, this is going to be happening. I said on the phone and one of the grandparents, dumbest thing you could say to a parent. And I am just furious. I step back, cool down and I go back and he says what you need to do as a Doctor, you need to bring people in. He brought me back in. He taught me those tools, okay? That was really building my confidence and my competence as a parent. I want to give you a little insight into what's going on inside of us as parents. How many of you have a loved one that's passed away? Boom. You hit the bottom of this little chart up here and slowly, you know, six months to a year later, you're starting to get better and then all of a sudden, there's an anniversary or a holiday and there's grief again. When you have a child with special needs, it's cyclical. Evaluation back for Carl. Give me the next one. They say he's at a third grade, second month level and the kid is 15. I'm getting better and I climb out of the ditch and all of a sudden, my nephew gets married. Carl says, daddy, can I drive? When does it end? The day he dies or the day I die. That's a lot of grief for us as parents. When the medical society understands that, focus in on this, it makes a difference. How do I spell a medical home or what have I seen that's been helpful for me? The first thing, go ahead. Next slide. A safe place. Second thing, clear, concise information that cuts to the heart of what I really need to know as a parent. Don't give me all the fluff. I don't need the poems. I want bullets. Tell me what I need to do, okay? Next thing I need, I need a family and patient centered care and I received that in such an incredible way in the original diagnosis and there in my medical home, okay? They're caring for me and my family and empower me to do the things I need to do. Increase my sense of confidence and competence and really a comprehensive network. Within six hours of Carl being born, knock on the hospital door. In walked a mom of a 7-year-old with down syndrome. Do you have any questions? it was parent to parent before it was called family voices in South Carolina. And I started volunteering with that organization. I started buying into it. Now I work for them. You guys, Title V, MCH p gave my medical community the tools it needed to do it right. You've impacted me forever because of it. And I will be engaged and now you guys are doing something really cool. You're helping to fund. Next slide. You're helping to fund the family voices. Okay? Around the nation. We've got these centers, a parent that will engage and help the families navigate through the health care system which is huge for me. Powerful, powerful, powerful tool. Pull the next slide up there. Family centered care. Some places we still have a lot of work to do. I just

Now I work for them. You guys, Title V, MCHB, gave my medical community the tools I needed to do it right and you've impacted me forever because of that and I will be engaged and now you guys are doing something really cool. Helping to fund. Next slide. You're helping to fund the family voices. Okay,

around the nation. That we've got these centers of parents that will engage and help those families navigate through the healthcare system which is huge for me. Some places have a lot of work to do. I just want to thank you guys for involvement and engagement. Sometimes you're out there doing this stuff and all it looks like is paperwork, okay? You're making a difference in our lives and you're making a difference in our families. [Applause]