

2011 AMCHP and Family Voices National Conference: Plenary IV -- Health Reform, Maternal and Child Health, and the Affordable Care Act One Year Later

02/15/2011 Omni Shoreham, Washington, D.C.

PHYLIS SLOYER: Wonderful tributes to Maternal and Child Health. Well, we're near the end of the conference. But we have saved the best for the end. I hope that you've enjoyed this. There have been three jam-packed days and I'll tell you really jam-packed. I said to somebody I was double booked on two or three occasions. And I also want you to remember that we're not going to be done after this plenary session. There are workshops this afternoon. But most importantly, there is a meeting at 4:30 on the Hill. There is a Hill reception and I encourage everyone who can make it to please do so. If you have questions about getting to the Hill reception there are answers for you at the reception desk. Before we get into our final session, I would like to take a moment to thank AMCHP staff and Family Voices staff and members who have helped to put this conference together. There is a remarkable amount of work that goes into putting this together and pulling it off with such grace and I would like to have the staff and members stand so we can give them a hand. [Applause] This is a session that I have been particularly waiting for I think you know that AMCHP is working to support states in their analysis and queries around what it means for maternal and child health programs with respect to the Affordable Care Act. Our new National Center for health reform implementation has developed a number of materials. I hope that you have seen them. I hope that you're able to use them in your work. There are a series of issue briefs that target the populations that we serve. Those around women's health and the Affordable Care Act, adolescent health and children and youth with special healthcare needs. I really hope you're taking advantage of that and with that, I'm going to introduce our panel who is going to be

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talking about the Affordable Care Act, health reform and a variety of other topics that are associated with it. What it means for those of us in the Maternal and Child Health community. The way the panel is going to work. I'll introduce all the panel members and they're going to have five to seven minutes to give you some remarks and then we will open it up for questions and answers. We'll start with Brent EUIG. He has been a tremendous resource for us. I think those of you who have received legislative alerts and a variety of issue briefs, they do a phenomenal job in keeping us informed and giving us very rapid fire information when we especially need it. Donene Feist is the director for Family Voices of North Dakota and runs one of their family health information centers. She is a nurse by training and a family member parent, which is probably the most important piece here. Donene has won several awards including a community health leaders award in 2008 and she was named one of five outstanding North Dakota with her work with children in special healthcare needs and has been involved in policy around inclusion for individuals with disabilities. Those of us who live in that world know how very important that is. She's been a tremendous advocate for the disability community. Dr. Rick Gilfillan is the acting director of the Center for Medicaid and Medicare innovation, CMS innovation and I want to point out that they're not the original CMS. He accepted the job directing the CMS performance-based policy staff in August and before joining CMS he was consultant for a consulting service, the CMS administrator, Don, accolades him with his knowledge and health systems and pay organization especially innovative care delivery such as accountable care organizations, patient-centered medical homes and bundled payment systems. From 2005 to 2009 Rick was president and CEO of a health plan and I have to say it was a -- is a very large integrated health system with

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750 physicians, 12,000 employees and very sizeable. And finally, but not least and very importantly, Dr. Kyu Rhee. He serves as the chief public health officer of the Health Resources and Services Administration. Prior to joining that he was program coordination at NIH and before that, he was chief medical officer of Baltimore medical system, which is the largest network of federally qualified health centers in Maryland. Now, what I was interested in he's board certified in internal medicine and pediatrics. For those of us working in the world of adolescent transition we know how important those double boards are. Received his medical degree from the University of Southern California. Did his residency at Cedar Sinai Medical Center in Los Angeles and he couldn't stop learning so he got a master's degree in public policy from the John F. Kennedy school of government at Harvard University. Thank you all for joining us. [Applause]

BRENT EWIG: What a pleasure to be up here not only with this panel but also with Phyllis on her last day as president of AMCHP and this morning we recognized her with our leadership and business meeting but together if we could just recognize her one more time for her leadership. [Applause] I can just say without question there are many lighthouses we would have slammed into without her guiding us. So we heard a lot about stories, we saw some pretty nifty dance moves here. I know this won't make sense to folks who were here on Sunday but we had a choir and there is this kid who stood right here and he had movements. He was never facing the right direction at the right time but he had moves. I couldn't resist that. I thought that was pretty cool. We heard from Andy Goodman and said there might be stories about mice and there are. I would love to tell them but I would like my job. What I would remind you last year at a session much like this

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somebody asked me a question and I didn't know how to answer it. It's hard to answer that because Mike had a rule that he would only hire optimists. That's how we operate. We challenged that a few times especially in recent days but try to keep that. So my story, I have become a new father again for the second time. [Applause] I can show you the obligatory smart phone picture. My 2 1/2-year-old, 10 weeks old yesterday. It is so joyful and so the story is I'm talking to the 10 week old a few days before the conference started and I said I'm going to speak on this panel on health reform. And she is only nine weeks old then but very advanced and said dad, wow, kind of political, isn't it and contentious? I was impressed. Born inside the beltway so he has politics in her blood but contentious is a 50 cent word for a toddler. She said what will you say? I said well, not sure but I'll try to say it carefully. Obviously where we've been in the last year has been challenging. It seemed the passage of Affordable Care Act and I have said to many audiences since I've been personally shocked to see that the politics of health reform didn't stop the day the president signed it. That's the reality we all face and you face daily in your states. That's where I want to start. AMCHP is approaching this work carefully because we know this is not easy work and wouldn't be easy work in the best circumstances but with the divisions and partisanship that's out there we've tried to gear our work to be very sensitive to the environment you're working in and at the same time provide the best service we can. The Center for health reform. Two minutes about that, I first wanted to mention the budget is on everyone's mind. If I could take a quick minute to bring everyone up to speed on the latest of what we know today. The house of representatives is beginning debate on the continued resolution that would finish off funding for fiscal year 2011. That expires on March 4. We all have done everything we can

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to let you know what's in that continuing resolution to the Title V, MCH Block Grant and other key programs. That's been a rollercoaster ride. Stories of people having to pick me off the floor two or three times after news has been announced the last few weeks. Where things stand today the current targeted reduction in the bill brought to the floor is \$50 million. That's a significant cut. We're watching with great interest and concern because there is a likelihood that amendments could be offered that would go deeper or possibly worse. So what we offer to you is your association we remain vigilant, a package of the minutes was released this morning. 451 pages. We've had staff combing through that to see if there is anything we need to know about and let you know about and continue to do that in the days ahead. I believe they're targeting a vote for Thursday evening. So expect potential alerts or updates from us through the week. That's where the budget issue stands. Back to health reform. We wanted to organize AMCHP to be able to say we want to provide the states with the tools and resources and strategies to help you optimize the options and challenges and navigate the challenges that you'll have in implementing the MCH related pieces of health reform. Another story I would like to tell we knew we were doing this session and knew health reform has been confusing to people and what is in the bill and what is not in the bill, where do things stand with implementation? The story is this. The subject in the story. The AMCHP staff said wouldn't it be great if we had a resource to give people an update on where things stand for key things. We put -- we wanted to have a document as brief as we could that would achieve that and so we got to work on this and the way things work in Washington is we look at what other associations have done. Steal from the best and make up the rest. We looked for a model that had the nice boxes here. We said let's start amending our summary. As we were doing

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that here is the first barrier, things were coming out daily. We finished it Wednesday. Home visiting data comes out. We have to add that. Ready to go to print on Thursday. The new allocation for the prevention fund come out. Let's go back. Friday we say that's it, the cut-off. We'll print it today knowing it will be outdated tomorrow. Another barrier, you said two barriers. I had to walk up hill to the other hotel to get to their business center to get these copied and the third barrier is I said we have it in color. I would like getting color copies. She said that will be \$2,700. And I say it's already got a date. Let's do it black and white. That was the third barrier. Not quite as pretty. This is your resource to take home for the things we've been tracking on your behalf to help you answer those questions. Where do things stand, is there guidance? Has there been a request for comments? Is there money available yet and so that hopefully is not as comprehensive as we like but trying to hit the high notes. The last thing I would like to close what are our plans for the coming year. We're approaching this carefully. With our board of directors on Saturday we have them very carefully examine policy agenda that our legislative and healthcare finance committee has put together. I can share with you the top three things are number one, protect and fund the MCH Block Grant. Number two is to optimally implement the MCH-related provisions of the Affordable Care Act. Number three, knowing the real new money that might possibly be available is the prevention fund, is to work on your behalf to make sure that an adequate portion of that fund addresses MCH issue. If it is doing chronic disease and work in with our partners in chronic disease, we think there is great opportunities there. So those are the top three policy issues and we've said within implementation of the Affordable Care Act we want to look at the immediate opportunity where there is money on the table and where to leave acknowledge it with

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our partners in the state. Opportunities to make sure we're your voice in Washington as dialogue gets underway in setting the essential benefits package. Looking at the Medicaid extension and how we coordinate outreach, enrollment and long term as we look to the 2014 date and see this moving forward. A big question about the health system's capacity and using MCH role to make sure that we have the right systems in place that we're linking with our Medicaid partners and doing everything we can to make sure that MCH is at the table as those decisions are being made. I'll stop there. We want to go through and have much wittier, better looking and insightful speakers coming up next. Let us keep moving. Thank you. [Applause]

DONENE FEIST: Good afternoon, everyone. Again, my name is Donene Feist the director for Family Voices of North Dakota. I told our two physicians that in case I pass out I was glad they were up here and right away Dr. Rhee gave me a bottle of water and said hydrate. So AMCHP members. Thank you for having a family member as part of this panel. I'm hoping today that I can talk about my family situation that we went through and I have a couple other family stories that I'll hope to not only talk about some of the barriers perceived and real but also ongoing opportunities that I feel like a family to family health information center that we have available to us. Some of the points that I'm going to illustrate is some of the impact, are we surviving but thriving? The financial burden and bankruptcy. Putting a face to the issues and some of the recommendation. If you want to put the first picture up. This is my family. This is my son's wedding this summer. I now am a grandma and only 29 years old [Laughter] All right. So -- like many, our family is not much different than many other families that are in the room today. I think over the last 20 years one of the things

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that I would like to say is that we were survivors and all the families in here are also survivors. We're survivors with a health system that hasn't made sense. A system that is confusing, fragmented and one that has become worse with each passing day until just recently. One of the reasons advocates told me long ago it really isn't about the barriers -- it's about the barriers but it is not about access barriers completely. It is also about our life situation and how it is confounded by personal beliefs, attitudinal barriers and limit patients to existing programs that really don't match the needs of our children and families. And I really want to express that. In our own family journey we fell through the cracks with ongoing diagnosis of all three of our kids. Each had a different diagnosis, a different system. Different set of rules, access points and barriers getting to the appointments, purchasing equipment, also the other bills that we had to pay for. Initially when the middle -- we had to drive 150 miles one way to get services for him initially. My husband and I work two to three jobs to pay the medical bills and with our best efforts we couldn't keep up. So we survived the humiliation of bankruptcy due to those medical costs that we incurred. All happened unfortunately that really was my last and we ended up paying the ultimate price financially. I don't think we would have survived if we didn't find a trusted other amongst our other families. I'm telling the families if you -- it's really important, I think, for all of you to find that trusted other and ask for some help. I think so often we're helping other families but we forget to ask for help ourselves and I want to stress that to all of our families here. Also I also believe that while we ask families about their health and maybe they're depressed but we really never ask them financially how it's going and I think that's so important. Sometimes we're giving therapy after therapy after therapy or buy this piece of equipment or that piece of equipment but do we ever stop to ask

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people if they can pay for it? And that's really important and who is going to admit that? That they can't pay for it? We feel like we're failing. I think we really need to consider among our agencies and organization who is the best to ask these questions and understand those issues. We don't want families to be subject to losing their house, their car and their mental health. So reform will help many families in obvious ways. I think together we understand to make sound systems change we must engage those that utilize the system. Family advocates have the finger on that pulse every day on what is working, what's not working and what it will take to make the system better for our families. I think the adjustments propel many of us in family organizations to stay involved and make a difference for other families. To increase the quality of living of special healthcare needs and its impact on families. In North Dakota through the sheer determination of my Family Voices of North Dakota colleagues we were the first state in the nation to implement the Affordable Care Act -- that's not there yet. The family opportunity act. I'm really proud of that. They really worked hard. [Applause] Reform continues to help us move forward in a place so we can have attainable healthcare for our families. I believe that the health information and education centers are an outgrowth of a determination of the advocates to see that families receive the help, education and information that they'll need to navigate this very complex system. So what better organized effort than to have these state-based centers staffed those living with those issues? I also think that the ACA provides a golden opportunity to partner with other family advocates and professional partners across the country. But we have to make sure we're including one another in that process. From the very top of the systems change to these family organizations, assist families each and every day. They understand that many systems that families encounter and at the

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table discuss what works and what doesn't work and I dare to say these family organizations are probably some of the best ombudsman for the programs that are available. So we really must continue to stretch across many systems and form a better partnership within our private and public systems for families. We know that all systems of care should be family centered, culturally competent and community based but how to get there if we aren't engaging the folks we need to utilize in the system? I want to leave that as food for thought. So let me introduce you to a couple of North Dakota -- three North Dakota families that are pretty hard working families that have seen the adversity of the healthcare system. This family is from Bismarck, North Dakota, both mom and dad are employed and have health insurance and a family plan. Jacob, the one with the hat on, is the one that receives most of his care in Bismarck itself. He is 16 years old, sophomore in high school. He likes a great work-out. He likes to hang with his friends. He has a girlfriend and Jacob has hemophilia. Treatments for his blood clotting disorder cost between \$50,000 and \$80,000 a month. Per I.V. clotting drug. He was covered under his father's health plan until he was 12 when he reached the lifetime cap on his benefit and then he was switched to his mother's healthcare insurance and now at 16 years old he was capping the mother's health insurance as well. This family has had good health coverage but the lifetime caps were not only emotionally painful but also providing life-saving treatments for Jacob and if they didn't have that, would put him very much in jeopardy and put the family in financial rue en. With the elimination of the lifetime cap Jacob will be -- grow into a -- he'll be able to grow into the adult that we want everybody to do and have a good life. So for Jacob it means that he'll have life-saving medication he needs to go to school and look forward to his future. Next slide. This is alley and Ashleigh. Both of

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their parents work. They use both private and public health insurance. Allison receives her care not just in Bismarck but also in Minneapolis, which is a seven hour drive. Ashleigh is on the picture with her, adores her little sister, she has also become a tremendous voice for her sister and other children with special healthcare needs. Alley is 10 years old. She likes to experiment with makeup. She called me at Christmas and told me she's running out. She likes to dance to high school musical. She has a very progressive and degenerative diagnosis and it affects every system including her brain. She's very much at high risk for developmental decline. She also has reached her lifetime max and Jennifer, her mom and I were fortunate to be asked to come to the White House in June for one of the press conferences of the ACA and that was a thrill to both of us. But she gets a weekly enzyme replacement therapy that assists her in breaking down what her body needs. The drug costs about \$8,000 every two weeks so you can imagine that this gets pretty difficult for this family. She also had a \$2 million lifetime max on her insurance policy. Before the ADA happened they estimated that she would hit that max by her 10th birthday. She turned 10 last Saturday. Despite a recent hospitalization for a spinal fusion put them close to reaching the lifetime max before she turned ten her mother says we don't need to live knowing we'll have a child for a short time, live with the constant stress of how to pay the medical bills from month-to-month, try to give our children as wonderful a childhood as possible, yet ultimately be forced to take them from cradle to the coffin. Despite our efforts to avoid just that. Jennifer called me on January 5th crying her eyes out. And I thought oh my god, what happened. And actually it was good news. Her insurance company had called and told her that her lifetime max had been eliminated and she was ecstatic. How would you feel if you had been in those shoes? So the next slide is the

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Keller and Reed family. They utilize private and public insurance as well and live in Fargo, North Dakota. Everybody has heard of Fargo because of the movie. Okay. Carson is 14 months old, born on October of 2009, a beautiful, sweet baby but he was also born with trisomy 13. Prior to his birth, his mom was put into a coma because of pneumonia. She continued to be in a coma for Carson's birth, few weeks of life. Cassie was told that he wouldn't survive birth but when she woke up from her coma Carson was still alive. Their story is a story of being blessed with a child despite the odds and not only survives his first year of life. Carson's story is a little difficult for me, however, because it does not have a happy ending. It will make you ask questions and hopefully not make you angry as it made me. The day after Christmas Carson stopped breathing. His mom performed CPR and he was taken by ambulance to the hospital. The medical assessment suspected that he had a seizure and possibly aspirated. After two days of being in the hospital, he was released with a physician's order for oxygen monitor. The hospital nurse contacted the vendors to provide the monitor. The dilemma was public insurance policies didn't cover the monitor. Private insurance policy stated they could only cover the monitor if a child was on continuous oxygen. He had oxygen at home but it wasn't continuous. The family believed the professionals would help get the needed equipment. They not only had one but they had two insurance coverages. Carson was discharged with a new seizure med although he was still sick throwing up discussions continuing among the insurance companies regarding the oxygen monitor. He was readmitted again New Year's eve. They concluded he had a spot on his lung, his heart was positioned backwards. They figured it was the heart pushing on his lung. After the discharge with the new anti-nausea medication and antibiotic and no oxygen monitor. Mom and dad went home, checked

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frequently. In the belief moment mom took a shower Carson passed away on January 4th. He had two admissions, two discharges and one unfulfilled physician order for a oxygen monitor. Cassie and Matt wonder and will never know had the monitor been approved would Carson still be alive today? The gift that Carson gives us goes beyond the love and nurturing but also that he will also teach us how to move from no to yes and how to develop appropriate and safe discharge plan identified gaps so the system can be made better. Urgency really here is while progress has been made there is room for improvement and children and youth and their families who care for them often cannot wait for consensus building and new regulations to be passed. What they need and want are sometimes urgent solutions because especially with life-threatening and life-saving issues. So where in your state do families and providers go to receive trusted and adequate information? In the era of which we have a click away lots of policies into a fact line we need that trusted information. Do we really need another committee or can existing groups shape that policy and influence around the table and guarantee that all players are present? Families need to be present by their peers, treated with respect and have equal partnership and. Who can help the families like those we talked about today? Who will help navigate the system? I believe our family to family health insurance centers are filling that gap but I think we could do better. In Washington and among other policy groups a lot has been discussed about agency outcomes, educational outcomes, but what about quality of life outcomes? Not only for the families, but for children who the system is for? Our grassroots family leadership organizations have a role to play. Many have personal experience and inside views of systems. They understand the criteria, what qualifies for el guy bi. how to assist families in navigating multiple agencies. Many of us have learned

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the ropes through the agitation. But really wasn't timely. Our new families need and deserve better. We need a system that is responsive, includes the real family voice at the table of policy. One size doesn't fit all. I would be mistaken if I didn't mention some of the special needs that happen in the rural states as well. Our rural residents especially in North Dakota are pretty proud, stoic people. They won't seek assistance though it's needed. For some families, it indicates they may be doing something wrong. There is a lack of understanding about healthcare coverage and benefits, resilience and where to find community based services. The needs in rural areas are compelling. Remember in the 1990s we had a great policies on telemedicine, those kind of issues. What happened to that innovative approach and why can't we get it going? People's health shouldn't be in jeopardy because of where they live and not in these days of technology. We also need to remember what about the communities that have time honored beliefs, customs and cultural practices? In closing I just wanted to say I hear the echo of our great leader every day who said, reminded me shortly before she passed away. Say what you mean, mean what you say, stand tall and press on. I know we'll have to press pretty hard to get where we need to go with Affordable Care Act now and you're all invited to North Dakota. Toughen up. [Applause] Be happy to show you around. But when you go back home I just want to say what are you going to do to make a difference? Because quite honestly I think our children, youth and families have waited long enough. Thank you. [Applause]

RICHARD GILFILLAN: It's great to be here. When I find myself giving talks I want to start with a story about patients. Certainly done that job, so thank you very much. Those are great, very moving stories that kind of set the stage for

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what I think the work that we're doing and talk about the work that we're doing with NCMS. Let me turn to that if I could and start by asking, how many folks out there know what the setup for Medicare and Medicaid innovation is, or is intended to do? Those lights are tough. Good. Let me, if I could then, take a few minutes to give you some background on CMS and the Center for innovation and like to kind of get out a couple of thoughts also about how we're focusing on women and children and where we think that population fits within the work that we're considering or that we're thinking about in the center at CMS. Let me also start by thanking you all for the incredible work you do every day in taking care of children and families in need. It is outstanding work and very important and oftentimes within CMS, because we're so focused at times on Medicare, Medicare issue is right in front of us we tend to lose sight of what goes on in that other world in the Candyland world of Medicare. She is an incredible advocate for all of you and as is Melanie, the head of our new Office of Federal coordinated care. We are constantly thinking about, hearing about, working on programs both Medicare population and Medicaid population. Don has the new administrator at CMS has given us a new mission. That mission is to make CMS a trusted partner in a constructive force for continual improvement in health and healthcare for all Americans. That's a new mission for CMS that goes far beyond what traditionally has been about paying claims and administering programs. And really commits us to look outside of Washington, out to rural states, out to cities across the country, and see what we can do to improve health and healthcare for all Americans. We know we need to do better for all Americans because we can't just operate in -- on behalf of Medicare and Medicaid beneficiaries. The same delivery system, same doctors, hospitals, providers caring for our beneficiaries are caring for everyone

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else whether they have coverage or not. Many more people have more and better coverage now than they had before. So we're looking for ways of accomplishing that mission. When you think about what that means, a constructive force for what? We think about a current healthcare delivery system that is in a fragmented state. Fragmented in the way we deliver care, fragmented in the fact that we have over time lack of visibility and people's journeys as they go across their life and go across different parts of the delivery system and it is fragmented in the way we, Medicare, Medicaid, in the way private payers support the system. We pay the health system to stay fragmented. And then we complain about the fact that it delivers fragmented care that isn't satisfactory to everyone. It doesn't make a lot of sense. That's where we are and the nature of what we're doing. What we envision is a different system. Not something we can create but something that providers in the community, in their community need to create. It is a safe, seamless, coordinated care system and that's the vision that we have and I think we all have and that, in fact, is essential to continuing to carry out the insurance-related reforms in the Affordable Care Act. We cannot afford to cover everyone unless we find ways to treat everyone better. So that movement from a fragmented care system to a seamless, safe, coordinated care system is the transition that we all face and I suggest you all face probably in your programs. We as CMS know that we have to transition. We have to move from the way we pay today to the way we pay and support providers delivering that care tomorrow. The Center for innovation was established specifically to help drive and aid that transition to a new care system. The Congress gave us \$10 billion over ten years. They gave us a clear path to a number of the traditional bureaucratic obstacles to making change and they said go out, find new care models and new ways of paying for care that don't support

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fragmented care but that do support seamless, coordinated care. That is our mission to go out and work with the delivery system and find, validate, diffuse, spread, give a model that will deliver the new care experience. How do we measure success? Three ways. Better health, better healthcare, reduced costs through continuous improvement. We have to reduce costs. We believe firmly that we can improve care and reduce costs and I've heard from folks today and last night about how you can do both when taking care of the most needy children with the most severe disabilities. We know it's possible in that segment and we know it's possible in maternal care. We know that better care can produce better outcomes and reduce costs across the care systems. We are interested in finding new care models. Interested in care models at the level of individual patient care. How do I provide the best OB care over nine months? Provide the best hip surgery? How do I provide the best cardiac surgery for congenital heart problems? How do we do that healthcare there? How do we coordinate care? Other mechanisms to coordinate care over time and how do we operate at the population level to improve the health and determinants of health in the population? We're looking for care models, new payment models at all three levels. Phyllis told me today what we should do and how we should go about -- right. Unless someone comes up with a better idea, she'll get a call and we're gonna work with her. That's a joke. I can't say that. But our mission is to look for those new care models that deliver those outcomes. We're interested in hearing from you all and from providers, physicians, hospitals, other care providers in your states from within your states, we're working closely with Cindy and Melanie to respond to increased -- the Secretary sent out a letter to governors recently laying out a whole series of new ways to interact with CMS to help address the fairly severe, as you know, budget

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concerns that they have particularly around Medicaid. We as an agency are in a position now to kind of be there in a much more vigorous way and more robust way to work with states and agencies within states to improve Medicaid and improve outcomes for your populations. That is out there. I'm sure your company will get that to you. We look forward to hearing from you and look forward to working with you to try and improve maternal and child health. Thank you for the opportunity to be with you here today. [Applause]

KYU RHEE: Thanks a lot. I don't know if we have that picture up but -- there they are, yeah. There they are. I had a great fortune this morning to take my daughter Ella, a 2-year-old behind there. This was very impromptu yesterday and good to have the mobile phone able to take the picture. She held Zoey, a 5-month-old, nice, robust five months. [Laughter] There and so this morning took her to her 2-year-old well childcare visit. I love reflecting on our two other speakers the importance of stories and statistics and in many ways to share a little bit about people and I loved how Brent gave this quote that I'll continue to use, steal the best, make up the rest. I'll use it in future talks. Reflecting on kind of my role at HRSA and some of the opportunities that we see as it relates to the Affordable Care Act and I just wanted to share a little bit of my story as a father here. And kind of the challenges, of course, in raising two little girls and for some reason Ella isn't talking much. She's saying one word now, she's two, up, up, up. I put her up, say something. So, you know, just understanding how challenging the healthcare system can be as it -- as Rick mentioned how fragmented it is and how the different resources that you want to connect to assure that Ella progresses normally developmentally and such is, of course, something even a provider can be challenged to do. So we're

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really excited about her growing development and the fact that she said up two weeks ago and appreciative of the broad range of providers helping us including our pediatrician. I have also served as a primary care physician in underserved settings as an internist and pediatrician and seen how challenging sort of the story that I heard from Donene about how these stories are so impactful and powerful. It is really hard as a primary care physician to be seeing patients once every 10 to 15 minutes and all the cross cultural challenges in underserved settings. The broader determinants of health that often come up in those conversation. It important to bring light to those stories. I learned this at the Kennedy school of government. When you look at a lot of policy changes, those were often motivated by extraordinary stories. Those stories made an impactful role to change policies. So the importance of listening to those stories is very important. So I'll now transition a little bit from that to kind of HRSA's commitment to children and we have an extraordinary portfolio that I want to highlight and we can have a further discussion on. The Maternal and Child Health programs clearly the MCHP bureau celebrating its 75th year. All you guys are familiar and part of that. That's incredibly important but I wanted to give a little bit of a frame of a broader quilt that HRSA supports as it relates to women and children. There is a lot of safety net programs as well as workforce programs that are very impactful to health centers which I'll talk about. The Ryan white clinics that serve those with HIV. The world health programs and policies. The organ transplant program which was on Valentine's Day celebrating the importance of donation and the importance of that program. Also we have workforce programs that look at the importance of primary care coordination. When you have a fragmented system. When I teach students I talk about if there is one word that represents our healthcare

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system it's fragmented. So a lot of what we're challenged to do is to integrate and primary care is an important role in that coordination and integration. So the national health service corps. In terms of the president's commitment to children and the role the Affordable Care Act has provided we have to remember one of the first actions he took when he came into office was the expansion of CHIP, right? Child health insurance program that boosted insurance coverage to low income families to 7 million to 11 million children. There are other benefits that relate to women and children from the Affordable Care Act. \$1.5 billion over five years for the maternal infant and early childhood home visitation program which I know many of you -- right? [Applause] Under this program as you're familiar nurses, social workers and others will visit expectant mothers and families in high risk communities. When I think about my role as a primary care physician in the health center setting how challenging it is to know there could be a program that compliments the work in the walls of the clinic that goes to homes that provides care and really helps assure a healthy start for these high risk families. I can't underestimate how exciting that program is to think about. The act also extends annual funding of \$5 million until 2015 for the 41 family to family health insurance centers. The program that Donene was talking about that is staffed by parents of kids with special healthcare needs and when you think about what is going on in so many parts of the country and the role of these social networks and the role of peer-to-peer and community health workers and the impact that that has had to really improve health, the importance of family-centered approach. We use that term or patient-centered approach. Families talking to each other is so important. And those centers are linked 170,000 families to Federal and

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state programs, clinics, special insurance pools and rehab services for children with disabilities.

Another initiative that HRSA is excited about. The Center for healthy weight. We were very excited about this initiative and how it will have a significant prochild component that looks at how we can promote healthier lives in families and children using evidence-based clinical and community-based interventions to promote healthy behaviors and environments. It's in line with the first lady's initiative on let's move and go to preventioncenter.org to look and learn more about that program. The act authorizes \$200 million over the next four years to build, renovate and expand school-based health centers. When I was in Baltimore medical system and the site that I look @ unity in DC here. School-based centers are so important. The proximity to address and alert yourself to risks and the partnerships that develop between the health centers and these schools to be promoting healthy behaviors and healthy activities and healthy environments and healthy places beyond just the walls of the four clinic are incredibly important. That's another exciting part of the Affordable Care Act. Now I'll just transition and highlight a couple more items and then really look forward to the discussion. Health centers, this is another part that I'm going to highlight here. The demographics of health centers, the highest risk populations, 90% are less than 200% of the poverty level creating 70% serving health centers are less than 100% of the poverty level. 40% are uninsured. 40% are Medicaid. Affordable Care Act provides over five years \$11 billion in appropriations to expand and expand the range of services that health centers offer. And this adds in addition to the \$2 billion that was a part of the recovery act by president Obama. The 19 million people served in health centers, 1/3 are children

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and adolescents and greater than 50% are women. Look at the national health service program that I was a been factor, this is an exciting part. \$1.5 billion over the next five years to grow clinicians who work in these underserved settings. This follows \$300 million that was part of the recovery act to expand the corps. These are a broad range of clinicians. If you think of the need of providing care to populations, you can't just focus -- of course we are very emotion -- emphatic on primary care. A nurse practitioner, a physician assistant. The other disciplines that are so important in the integrated model and is health home approach. Oral health and behavior health providers, social workers. A broad range of disciplines need to be represented to provide that integrated, coordinated care to those children and those families. So we're very excited about the corps which two years ago only had 3600 people in the field. Thanks to president Obama's leadership we expect that -- the ranks there to reach 10,500 primary care clinicians by the end of 2011. So in closing, I just want to highlight some of the points that I mentioned that HRSA is incredibly committed to children and women and not only, of course, through the Maternal and Child Health Bureau but through the broad range and programs that HRSA supports. The investments in primary care and public health. Home visitation, family to family information centers, school based health centers, community health centers and the national health service corps and we're very excited about the role the Affordable Care Act has in terms of assuring that we can provide the highest quality care to the most vulnerable populations. During these tough economic times the importance of this work and the challenges that lie ahead can't be understated. And on behalf of HRSA and Dr. Wakefield I want to thank you and the extraordinary work you do, the commitment that you have and we often have this challenge when you had in health centers when we had

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limited resources and we saw potentially the resources were going the dwindle and we had to be creative. These times will challenge us to think creatively about how we can do things and it's going to be very important that we work together in the months and years ahead for this. So thank you very much. [Applause]

PHYLIS SLOYER: We have a very short amount of time for a few questions of our panel members. Do we have any? Trying to see hands up out here is impossible with the lights. Dr. Homer.

Audience Member: Charlie Homer from -- [inaudible] The question for the doctor -- [Inaudible] I know you're under enormous pressure to show immediate cost benefit in the healthcare-related dollars. I just wondered how you were thinking about that and if you have any suggestions for how they're focused and might be able to address those topics within the first year.

>> That's a tough question. That's a great question. I think as we think about the different initiatives and models that we're going to test. We thought about -- you come up against a problem of portfolio management. That is like if you're investments, you like to select investments that are different and have different characteristics to optimize your results over time and the same is true in thinking about what are the initiatives that we should tackle? And therefore when you think about different projects, what are the criteria you use? Some of the criteria, some of them we'll use will be we want to be diverse and spread our activities across the entire population. Want to do the rural, urban and spread out across the country. We want to be short term, medium term, long term in terms of seeing outcomes. And I think -- and we also know that we need -- we have a fundamental criteria and that is in the Act, the Act says we will find new care models and new ways of

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payments to reduce expenditures and maintain same or improved quality. So we have to keep our eye on that ball and I guess what I would say I think it is hard for us to look out and say 10 years from now we're going to see a reduced expenditure and so we're probably going to have to be mindful about looking for milestones along the way that allow us to evaluate what is happening on the plus side and similarly we'd like to be able to see quality outcomes. I think on the quality side it's more straight forward. We can see things and we can find intermediate milestones. We'll need to be mindful about that and I would suggest to folks out there in thinking about this specific issue of where will I see the impact and the beneficial impact for children, I'd say think hard about how we can structure care models, tests of care models, evaluations of care models in ways that produce intermediate milestones if they're really long term that would justify changing the system to pursue those models. Fundamentally our business is about if we can demonstrate is care model does, in fact, change the cost of care and improve quality, we can go to the Secretary of Health and Human Services and ask them to change Medicare/Medicaid regulations so that that new care model is supported in the future by CMS. Other thoughts you all might have about that. It's a great question.

>> One or two more questions.

BRENT EWIG: Can I mention just -- with attribution I should have added. From the former commissioner of health in Tennessee. That's it.

>> Thank you, Brent.

>> I mention the AMCHP -- real quick the opportunity to introduce you to Carolyn Mullins. Our new associate director. Senior advisor, Josh brown, many of you know who handles our appropriations work but I would remiss, the vast --

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apologize if I'm stealing someone's thunder. I want to make sure the staff is recognized, too.

>> Thank you. Do we have any more questions? One more question.

Audience Member: The question is. Where do you get all the money to fund -- [inaudible] Just wondering where you get the money for the reform. Are you getting Federal dollars or just redirecting the current budget you have or how do you find ways to be more efficient and have more programs available?

>> Who is the question directed to.

Audience Member: Anyone who wants to answer it.

>> Probably the two Federals.

>> Go ahead. [Laughter]

>> So we do -- the fiscal 2011 budget hasn't come out so there is a continuing resolution to decide what that budget. Once that gets appropriated, then we will sort of know what our budget will be. So a lot of the references that I was making was related to the Affordable Care Act and those appropriations that are in place. I do want to do another quote. I love your quote but I don't know who to attribute to this. If you aren't at the table, what are you? You're on a menu. You're probably on the menu. So make sure that families are at the table and Maternal and Child Health is at this table, too, right? But I do want to also reflect, Rick made a good point about care models. I would be remiss in not representing HRSA's care model in terms of the community health centers. As I mentioned, they served the highest risk population. If you look at the metric that we collect and quality indicators they're often better or as good as other settings and the

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affordability or the cost for a patient is \$610 per patient for year.

Definitely something to be thinking about as those, you know, and the Affordable Care Act does have a significant investment.

>> Our situation is actually we're very fortunate. The Affordable Care Act appropriated \$10 billion to be used over ten years to pursue the work that I was describing. So those dollars have been appropriated already. And we're just -- we periodically engage with our friends at OMB and other places to get them to allow us to spend some of that money. But it is appropriated. I want you to know that the -- back to this point. Just so you know the folks at HRSA are working hard for you, they were in my office between 6:00 and 7:30 on Friday spending my -- bending my ear about why it was important for us to work closely with them. So we in the Federal government, I think that's a fair indication of how in the -- in this administration, we're working really carefully together to kind of deliver a logical kind of outcome, a logical approach, if you will, to folks like you all out there who are trying to take care of families every day. So we are open to guidance and like to hear it as we're coming across ways that don't look that way let us now but that's our intent.

>> This resource has grants already made. Mandatory appropriation. The Federal grants. It gives the opportunity for AMCHP to work on this. We used some of the MCHB support. We have new support from CDC, Kellogg and Commonwealth foundation that we really appreciate. A chance to recognize them and thank them as well.

>> Of course, the family to family information centers are fund you had through the Maternal and Child Health Bureau. Thank you, all of you, this was an exceptional panel. [Applause]

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>> And certainly if you've got any more questions, that AMCHP can help you with, make sure you see Brent. You will tag team him. Okay. I'm going to ask our new president, Stephanie birch, to come up to the podium and our past president -- past president Nan Streeter to come up to the podium. Before we move to our afternoon workshops, we're going to take a moment to recognize our outgoing leadership and our incoming leadership. As you know every two years the presidency rotates and I'm rotating off and we'll welcome Stephanie in a minute as our new president. But I would also like to recognize a member who is rotating off, Nan Streeter. Our past president until today. Nan has really been the foundation of moving our association membership and board forward after a period of rather tumultuous times until we got Mike and our AMCHP staff that we have today. So I really want to thank Nan for her leadership and for her perseverance and her just exceptional personality as a president and past president.

>> Thank you. [Applause]

PHYLLIS SLOYER: We gave Nan a spa certificate this morning so she can really enjoy that. And before I turn it over to Stephanie, I'm going to leave you with some -- my thoughts and memories, very briefly. When you accept this position, you're challenged with the language in the beltway speech, even for those of us who have worked in this field for over 30 years. For example, if we're concerned about the trends in health and healthcare, we may approach HRSA, MCHB, CDC, act or even CSTE. However, when we want to challenge CSTE with new quality measures we will probably look to AHRQ or CAMI but we know it's -- who better to assist us with information than NTF? I was perplexed by the new lingo around Life Course or was it life span? At first I thought we were joining AARP but

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they aren't interested in ART and do not have linkages to MLD or SAKUM and we look at the early years of life we encounter so many letters that I know I have a legitimate DSM diagnosis. [Laughter] We can start in the -- are challenged with NBF to address such things as EHDI, skid and perhaps CCCHD but not PHLI. Let us not forget NCBDDD, who may work on CCCHD. Of course, we need to develop vital ECCF and include systems for AFD, including essential screening using MCHAT, ASK and BDI2 in coordination with spark. Our friends wonder where we attain our terms. Have you ever dealt with FERPA as compared to HIPAA especially with HIE and HIT invading our world? If we become a little volatile, help is right around the corner through nip not to be confused with the candy. Of course, it is less about intentional volatility, otherwise we wouldn't have so much to do with DOT and the DMV. After all, we should build family resilience from our newest venture with ACF as well as other groups that deal with interventions like HIPPE, not to be confused with the term describing those of us in the 60s or 70s of the previous century. My knowledge has been expanded through our MCHLI as well as our programs and did you know there are several PHLI? Our MCH world? Go figure. I am sure there is so much more but I honestly have CRS syndrome. So it's a good time for me to hand over the gavel. Thank you for all that you have taught me and the opportunity to serve as your president. And so now, I would like you to welcome an exceptional woman, a nurse practitioner and just an extraordinarily individual who is going to serve as your president, Stephanie Birch from Alaska. [Applause]

NAN STREETER: Let us give a standing round for Phyllis and her leadership. [Applause]

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STEPHANIE BIRCH: Many of you, I had no idea you had such an extraordinary repertoire of acronyms, many of you may not realize how long Phyllis has been a leader in this organization both as board president but as I understand treasurer, board member, committee chairs. It goes on for years and years and years and I'm so pleased that she'll be staying with us for another couple of years to help provide her insight and wisdom. The AMCHP board presented Phyllis earlier this morning with a donation and Phyllis, true to her advocacy, insisted that this donation go towards advocacy for AMCHP and so for that we really thank you. She was also presented a signed poster from the AMCHP staff and a gavel. How fitting for you. I do think you ought to make it into a rap song, Phyllis? I could see something in the making. I would like to also introduce our president elect Kathryn Bradley. She did send a few words I would like to share with you. To my AMCHP colleagues, thank you for electing me president elect. When I saw I was on the slate with those women I was honored to be part of such a strong group of AMCHP leaders. My apologies I can't be here in person with you today to personally thank you but my public health division is presenting its 2011-2012 budget at our state ways and means committee. As was previously stated, Kathryn wrote I firmly believe if you're not at the table you could be part of the menu. And the hard choice was for her to stay home and present in Oregon. She writes AMCHP is an incredible organization pulling together the voices of special health needs of children, youth and families. State MCH leadership and staff. The public health faculty, many advocates are all committed to a common cause to improve the health of all women, adolescents and children. This is a critical time in health discussions in our country and in times of change it's important to remember there are also times of opportunity. Working together and learning from each other, we can influence the future of

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MCH. She writes, I look forward to working with the talented AMCHP staff under the guidance of Dr. Michael Fraser, the AMCHP board and the leadership I hope to provide for you as well. The experience of each state and family bring to our collective efforts. Thank you, signed Kathryn. So a few words for you today regarding my interest and what I hope to focus on over the next couple years. AMCHP is a strong and vibrant organization. We have many assets, including our members, most importantly, our very competent, energy staff and the board. As we face the uncertainties of the Block Grant and its status of all of our special grants, the support of our Federal and state representatives elected leaders, we're going to need all of these assets and they all equate to leadership in order to help MCH move forward. My presidency hopes to focus on leadership and I want to talk a little bit about what my vision is about that. My definition of leadership is straight forward and action oriented. Set a vision, rally others around it and work together to achieve it. Defining leadership is simple. Doing it is tough. Leadership takes commitment, fortitude to see through the process, a willingness to listen and compromise. Leadership is a journey. It's a team sport. But when it's done well, the rewards are awesome. I'm committed to these next two years of working with our talented AMCHP staff, the board members, Federal partners, leadership in our Schools of Public Health and the AMCHP members to continue our work together in developing and fostering new leaders. Helping to develop our new state leaders is one of my priorities. We started this year with AMCHP's kickoff for newly revised new director mentor program. 10 of our new state MCH and children and youth with special healthcare needs directors are doing a year of study to work with seasoned leaders. A big thank you to AMCHP staff and her work in nurturing this to happen as well as the input and

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leadership of Valerie, Sam and Kathryn. This program is poised to help develop new state leaders in their roles and support their success and longevity in their positions. This is leadership in action. We have the opportunity yesterday to see our youth and young adult leaders in action. What an outstanding panel that was. I hope you agree. I think the work that AMCHP is doing around adolescent health and youth development is outstanding. Wouldn't it be something to have a youth-led, youth-directed and youth-sponsored leadership day attached to AMCHP's conference next year? [Applause] Supporting our young adults in graduate school through sponsored internship programs and two year fellowships offered through CDC are a great way to mentor emerging leaders. If you haven't had an opportunity to have an intern or fellow at the state or local level you've missed out on something. They are truly outstanding folks to have with you. I would like to give a shout-out to all of our MCH students. If you're in the audience I would like to recognize you by having you stand and our LEND fellows. They're there in the back. [Applause] Five of them are from my home state of the University of Minnesota. Finally, AMCHP's work on growing with Family Voices and family leadership development continues to reach new heights. Family delegates in the states has been tremendous. Note the growing list of family delegates on page 13 of your program guide. Again, under the eyed gans of the family and youth leadership committee former and current leaders, Amy and Ruth and Robbie, the AMCHP staff, family mentors and two family representatives on the board and the new -- a new group of 11 family scholars who just completed their year of study. 12 new ones will be picked this year. I look forward to the work they affect in their communities as a result of their new skills. My hope is that we can take this leadership training to the next level to effect change not only in

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advocacy but also to infuse family leaders in all states to help design healthcare plans, participate in writing policy and legislation and be visit lecturers and professional education. These are examples of leadership in action. I'm committed to working with you AMCHP members, the board of directors, the outstanding staff to build our MCH leaders in all areas. Now what is required more than ever is to lead, to show people where we need to go, to get them to come along with us, to reach new levels of health for all women, children and youth and families in our nation. Thank you. [Applause] Now I would like to have the -- it's time for regional baskets. The last three regions. I want to call up regions 8, 9 and 10 please. If our youth were here they would have been fighting over this. Joni Bruce from Edmund, Oklahoma. [Applause]

>> Good afternoon, I'm Caryn and I'm from region 8 from the State of Colorado. Region eight includes collaborative, Wyoming, Montana, North Dakota and South Dakota. Our basket this year is an impressive display of regional planning and that many of the additions were not purchased at our home airports. [Laughter]

>> The winner is Yvette ETHERN. . [Applause]

>> I'm representing region 9, Arizona, California, Hawaii, Nevada and the territories, Pacific territories. Want to thank them in particular because they got here for 24 hours on a plane to get here. By the time they are okay with the timing of being here they're ready to leave. I especially appreciate them coming all this way. So thank you. And our regional basket represents the region and we also have a toolkit for completing the home visiting search. So this should be able to help a lot of people. I'm sure everybody is anxious to go home and use the toolkit we've supplied in region 9. It's about a line

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item. The winner is Andy Roche. From Atlanta, Georgia. Sandy Roche, is Sandy here?

>> I'm representing region 10, the last region. We are small in size -- number, not in landmass. We only have four states but we're the fun region of Alaska, Oregon, Washington and Idaho. In our basket we have some great stuff for breakfast. The winner is Kathy CAFFERTY. [Applause]

>> All right, so we're ready to close here. I would like to have everyone join me in our afternoon workshops which start in five or ten minutes. Don't forget about the Capitol Hill reception in the HART building in room 120 starting at 4:30. Good luck to all of you. We look forward to seeing you all back again next year for an even better presentation. Thank you so much. [Applause]