

AMCHP Annual Conference, 2010

Moving Ahead Together:

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

Plenary V

Health Care Reform: What's Next?

March 6-10, 2010

MICHAEL FRASER: A wonderful collection of regional baskets here to present.

You can turn the music off, that's cool. Thank you.

I just want to thank all of you who brought items for these regional baskets. I think this year's baskets were incredible. We have mango bon-bons from Region 9, things from Guam. We've got Moose socks from Region 10. We've got corn; what region would that be? Seven. We've got a Wyoming sweatshirt, water bottles, and Moose droppings for dessert. So, I want to give these away, but before we do that, I'd like to ask if Liz Collins from New Hampshire is here. Liz, are you here? Liz, you are the winner of an iPod Shuffle from the exhibit Scavenger Hunt. Congratulations.

And now we have our Directors from each of the four regions here to introduce themselves and to draw the next set of winners. Congratulations. Just give them a sec to turn it on.

MELINDA SANDERS: Good afternoon, I'm Melinda Sanders from Missouri, and I represent – I'm the Director from Region VII, which is Missouri, Iowa, Nebraska, and Kansas. And I'm telling you, we have an awesome Albert Pujols t-shirt in the Region VII basket. So, whoever wins it, I'm telling you, everybody in the room's going to want it. Especially if you're a Cardinal fan, like I am.

MICHAEL FRASER: Okay, and the winner is --

MELINDA SANDERS: Well, it's Sharon –

MICHAEL FRASER: Sharon Fleishfisher. From Wisconsin. Sharon, are you here? Come on up and get it. You can come look through it. Congratulations. Now, our Region VIII Director from the great state of Colorado.

Director: The perfectly rectangular state of Colorado.

MICHAEL FRASER: That's right.

Director: So, which one is it? This one? Okay, Well, Region VIII, I'll dig way down.

MICHAEL FRASER: The one that says Mike.

Director: The one who said Mike. Susan Vandal. From Rhode Island.

MICHAEL FRASER: From Rhode Island. This is the third Rhode Island winner in this drawing. Something's fishy ****. Susan are you here?

Audience: She's on the Hill.

MICHAEL FRASER: She's on the hill, all right. She gets two baskets. She wins all three baskets. We'll make sure she gets it.

LES NEUMANN: Les Neumann from Region IX, California, and I was trying to think what our biggest distinction – we're the region with the most time zones.

MICHAEL FRASER: That's right.

LES NEUMANN: We go from Arizona, California, Hawaii, Nevada, and the Territories of the Pacific Islands. So, I actually should know how many time zones, it's about five or six times zones. So, that's our distinction. And we've got a great basket.

MICHAEL FRASER: Could we just take a second and ask our friends from the islands to stand to be recognized? They took two days to get here, and two days to go home. Thank you guys for coming.

LES NEUMANN: I think that's the happiest I've seen them is when we told them they could go home. I think they're ready to go home; it's been a long trip. I lost my glasses. So.

MICHAEL FRASER: Oh, I can help you. Kathy Cummins from West Virginia. Region IX basket. Congratulations. You are the winner of all kinds of great stuff including chocolate macadamia coffee, a jack-a-lope postcard, plenty of stuff. And now, our Region X director, otherwise known as Region 'X'.

MARIA NARDELLA: I'm Maria Nardella from Washington State, and our region is Washington, Oregon, Idaho, and Alaska. And I'm the last basket, so really, get your good vibes going because this is your last chance for one of these, but it's going to be my name, I can just feel it. Annette Phelps.

MICHAEL FRASER: From Florida. Congratulations. Thank you. Let's give everybody a round of applause for their contributions for some great baskets this year. Our program will start in about five minutes. Thank you.

[Break]

NICHOLE: My husband, Tim and I, we have three children. Roman is 22, my oldest. Heather is 20, and I really say I only have one child because I have a 17-year-old, the other ones are adults. My daughter, Heather, she was born two

weeks before my 21st birthday and she was diagnosed with Down's syndrome. Immediately after her diagnosis, they called in a pediatric cardiologist, whom I had seen just a few years before when I was under 18; he was my pediatric cardiologist as well. So, he came in and he discovered that she had two holes in her heart. They said that they would closely monitor them for a while to see if they were going to close up, or get larger.

Interviewer: And what happened?

NICHOLE: They didn't close up. I got involved with Title V. You know, we were young married couple with two small children and my husband didn't have health insurance through his work, so first they wanted to do a procedure, a heart catheterization and they put us in touch with the Title V program in our state and they paid for the procedure and then they recommended that we do surgery, and we looked at other options. Maybe if we moved to a lower altitude, would that help take some of the pressure off the holes and would that close it? But they opted to do surgery when she was 16 months old. So, the Title V program paid for that as well.

My husband had to change jobs to get better health insurance coverage, but we couldn't afford the coverage – it was too expensive, or we wouldn't have been able to afford to pay our rent. So, then they ended up paying for her surgery. She had open heart surgery and fortunately that we had them because she did get

complications following surgery. She got a blood clot in her aorta that shut down blood flow to her kidneys and her heart ended up doubling in size after the surgery. She almost died. She went home for one night and we took her back to the hospital the next day. The doctor came in and her heart stopped right then.

They got her back on the ventilator, heart/lung, and they didn't know what was wrong and they said they didn't think she would make it through the night. She ended up being in the hospital for almost two months, which was only supposed to be a two-week stay, so it was very fortunate that the Title V program was able to help us out at that time. And my husband missed a lot of work, and it was a really hard time for us.

You know, I'm a big supporter of Parent-to-Parent Support. That's how I got involved with Family Ties of Nevada as a parent-volunteer talking to other parents. So, if a child was born with a disability and they wanted to talk to another parent, then they would call us and we would connect them. That is really neat. I am involved in our Downs Syndrome, Northern Nevada Downs Syndrome Organization in Nevada, I'm a board member. And we do family gatherings and just really – it's very important to me that parents talk to other parents and have that kind of support.

Our biggest obstacle is, now that she's older, transitioning from different children health programs and finding services and healthcare coverage and for as she gets older.

We're a big advocate for our children to be able to grow up, be independent, have self-determination, and be able to live lives like everyone else. When we were close to losing her, that changed, I think my whole attitude and my family's belief that we wanted her to be happy and to be able to be a part of the community and do whatever anyone else could do. That became our major goal, you know, because it got so close to losing her at a young age.

I'm involved with our Title V program as well right now. We have an advisory council where they have parents as well as youth, young people, that advise them in their programs to keep them parent and youth friendly. So, I'm a little bit involved in that and it's really nice. That came out of one of their grants that they had to establish an advisory council in the state.

Encourage families to tell their stories, and talk to their legislators and pushing for healthcare reform and insurance coverage for children. I think what I want families to do is tell their stories and their challenges with health coverage and being able to provide health insurance for their children. And have that continued funding because the funding has changed a lot since we were able to access it. And it was really good for us, but I don't think that they are able to offer the same

assistance that they did 18 years ago to families now. And what a relief it was to have that at that time in our lives. So, I'd like to urge families to tell their legislators to support Title V and keep that funding available so families can have that because we did almost lose her and what would have happened if we didn't have that support from them.

[End Video]

STEPHANIE BIRCH: Good afternoon and thank you for joining us in this important luncheon session on health reform. Nichol's story demonstrates the need for health reform and it's a vivid reminder of how the tough choices and challenges that families around our nation have to make every day. It also shows the importance of Title V, even for families that are insured and have access to healthcare.

My name is Stephanie Birch. I'm the President-Elect for AMCHP, and the MCH and the Children with Special Healthcare Needs Director for the state of Alaska, Department of Health. AMCHP has spent countless hours, as you know, on the topic of health reform. Most recently, tracking and analyzing House and Senate bills advocating for Title V and preparing us for the changes in opportunities in our health care and public health systems.

Before we get into the content of our panel and town hall meeting today, I'd like to take a minute to recognize some of our colleagues who are doing amazing work in the states. We have three best practices winners to congratulate today. The best practice results are from a rigorous process of peer review and evaluation that indicate effectiveness in improving public health outcomes for our target population.

A best practice is defined as having been reviewed and substantiated by experts in the public health field according to predetermined standards of empirical research, is replicable and produces desirable results in a variety of settings, and clearly links positive effects to the program and practice being evaluated, and not to other external factors.

I'd like to take a minute to have the Best Practice Committee for AMCHP stand up and be recognized, please. You can find out more about our Best Practices Program and find best practices by going to our website at www.AMCHP.org in our Innovation Station page. Information about our award winners can be found inside your award book on page 17.

Our first Best Practice Award is for the Oregon Youth Transition Program. And accepting this award is Katherine Bradley. Katherine, can you join me on the podium please. Congratulations.

KATHERINE BRADLEY: Thank you very much. I just wanted to say a word to the folks who run the program, The Oregon Youth Transition Program is actually not under Title V; it's housed in our education system and is a very strong partnership that has been in place in Oregon for over 20 years. They were not able to come, so I very graciously accept this award for them and will be going to their annual meeting to pass it on. Thank you.

STEPHANIE BIRCH: Thank you. The next state that we're recognizing for Promising Practice Award is to Rhode Island, or Rhode Island's Pediatric Practice Enhancement Project. And Anna Nuvalls and Deb Garnall are here to accept that award. Are they here? Okay good. Congratulations. Do you have anything you'd like to say?

MODERATOR: So the Pediatric Practice Enhancement Project started about five years ago as just a vision and kind of a plan to build off of some great groundwork that Dr. William Hollins had laid the foundation and for in Duranwadiga, Rhode Island. And so we kind of worked with our partners and try to bring this model out to some community practices and it's been really well received in our state and even nationally, lots of you folks have asked us about it. And we're excited to talk about it and feel this is kind of a stamp of approval for a project. So thank you, thank you.

STEPHANIE BIRCH: Very good. Thank you. And finally, somewhat ironically, we are recognizing emergency practice from my state of Alaska. Our in the name of our award is Pediatric Disaster Preparation Project and Debbie Golden is going to come up.

DEBBIE GOLDEN: Well, the irony in this is that Stephanie really spearheaded this project. And I was happy to be a part of it; it was fun working with her on it. It was a really model of collaboration for our state and a heartwarming important effort. So thank you very much.

STEPHANIE BIRCH: So, thank you all. I challenge all of you to submit at least one best practice for your state to be considered by the Best Practices Committee and please visit our AMCHP.org website for assistance.

So, and now, we're going to talk about health care reform. Where are we now? Where are we going? What's happened? And what is happening? And what could happen in the future? Are all questions I think we are asking ourselves and our policymakers looking at the real possibility that something will be pushed forward and healthcare reform will happen this spring.

We have several MCH leaders here today to talk about this most current and important issue. We have microphones that are situated out next to the tables. Each of the panel members will be offering up some of their insights, based upon

their experiences in the organizations in which they represent, and we're then going to turn up the house lights and open it up to questions. We hope to have a less raucous town hall meeting than perhaps some of our representatives have experience in their home states. But we hope will have a spirited discussion at the same time, and that you'll take this opportunity to ask questions or of four very talented and knowledgeable policy folks here.

So first I'll introduce each of the folks and just very briefly tell you a little bit about them. I think we know Mike Fraser, our Chief Executive Officer and Brent Ewig, who is the AMCHP Policy Director and works with our legislative and healthcare advisory finance team. They work to establish AMCHP's positions and do an analysis of the current and voluminous health care legislation that has been coming forward.

Marsha O'Malley. She is going to speak first. She is the Executive of Family Ties of Nevada and member of the Family Voices Policy Committee. And I should mention that the story that you heard today about Nicole comes from her home state. Marsha brings a significant amount of policy experience to our discussion today, especially related to families, family involvement and family centered care.

And to her left, I welcome Bob Hall. And he is a friend of the American Academy – excuse me, he's a friend from, he's a friend of also. Hopefully he's a friend of. Friend from the American Academy of Pediatrics where he is the Assistant

Director of the Washington Federal Affairs Office. And he's been a lead advocate for children and the pediatricians throughout healthcare reform debate and also leads a Washington-based coalition of children's advocates known as the Children's Health Group. And I understand it's an interesting group that gets together on a regular basis.

So, now for our session, we're going to have moderated discussion, as I mentioned, and then open it up for town hall questions. So, Marsha, I'm going to have you start.

Marsha O'Malley: Okay, I thought you guys were going to do a review there.

Stephanie Birch: Oh, that's right. I'm sorry, yes. Brent's going to do a little opening and bring in the discussion. Thank you.

Brent Ewig: Sure, sure. So I think –

Bob Hall: No jokes Brent, please.

Brent Ewig: Then I have to throw away my presentation. I try to be funny and my wife has told me that I'm not. And she's – when we were dating she used to ****, she used to give me a courtesy chuckle and I don't even get a courtesy chuckle anymore. I've given up.

But I think one of the things that is on all of your minds is, where are we today on health reform. And so, we didn't want to spend a lot of time on this panel talking about process because it is messy, but essentially just that we all start at the same place. Where things stand right now is that the President a couple of weeks, as you all know, convened a summit at the White House and said that prior to that, he had a plan to move forward and the plan essentially boiled down to taking the bill that the Senate passed on Christmas Eve, making about a dozen substantial changes and working forward with that as a basis of discussions. I think there were attempts again to incorporate ideas from both sides of the aisle, and it's becoming abundantly clear, you know how that process is playing out.

But the best information we have right now is that that's the conventional wisdom is that Congress intends to move forward to seek a final vote on a health reform package that would be largely based again on everything that was in the Senate bill with a handful of changes that the President has suggested and that, as we speak, the word is that the Senate and House are negotiating the final language. And I think some of that is at the Congressional Budget Office being scored so they can get a final budget estimate, and then the very latest is that they intend to bring it to the floor starting in the House for a vote, I believe next Thursday is the target right now.

And so, that brings me to something that I've been repeating to you all for months and months now, which is the next few weeks are really going to be crucial and I know you probably remember maybe last June I was saying that, and last march I was saying that. So, I do apologize for repeating myself. The other thing I've been repeating ad nauseum is this question of, what do we really think is going to happen? And the way I answer that is to quote Yogi Berra, the great Yankees Catcher who said, "Predictions are hard, especially when they're about the future." Thank you for the courtesy chuckle out there. I appreciate that. I'm going to report that back home.

And so, we're in touch every day with the rumor mill that Washington D.C. and that's where things stand. So, having the knowledge that they're moving forward with the Senate bill gives us at least a little more solid ground to proceed in this discussion and that was really the intent of having a short summary for you all on the table. Again, it's a moving target because the President has suggested changes that aren't reflected in this summary. But we wanted to send you all home with something concrete that's short, and that's the reason we really tried to boil down that humongous bill into some key provisions. It's not everything, but we really tried to highlight where we think some of the most important things that will change both public health and Title V practice will be coming down the pike.

The last quick thing I would just remind you all is, AMCHP's Board of Directors, in November 2008, put together a set of principles to guide all of our work in

advocacy on health reform. And those principles really boil down to three simple propositions. One is that we should cover as many Americans as the budget will allow, and we of course said we should over all. Second, that the benefits package should be adequate to meet the special needs of women and children, and especially children with special healthcare needs. And then the third and I think every group that cares about healthcare cares about those two things, so we were in solid company. Our third principle was a little bit unique in the public health field which is that we wanted to acknowledge that health insurance coverage and access is essential, but insufficient to improve health and therefore health reform needed to make investments targeted to public health, particularly to strengthen Title V. And so that's an area that – thank you for the courtesy applause.

So, that's the area where we really have focused the majority of our advocacy. And I would just say upfront that Stephanie referenced the raucous town hall meetings, I think it's become abundantly clear that this is a very intense atmosphere that this is being debated. And from the beginning, we have tried to recognize and acknowledge that those who would be working in state Title V programs work for health commissioners and Governors of both parties. And so where we've tried to focus our advocacy is very much on those, what we think are non-controversial provisions under the third bullet that talk about making investments in state programs. We've been in very close contact with the Governor's Association and the Association of State and Territorial Health

Officials throughout this process to make sure that any public advocacy we did would fit in things that they were comfortable in. So, we have been very clear not to weigh in on the Medicaid expansion proposals that might have a negative fiscal impact on the states and allowed -- and deferred to the NGA to really lead the advocacy for states in that. And we just wanted to make sure that we were keeping on solid ground with you also. The caveat that's been somewhat of a limiting rate in our advocacy but really has focused us on that third bullet. And I think that would ****.

Stephanie Birch: Marsha?

Marsha O'Malley: Well, I just have to say, coming to D.C. is kind of like being back at home playing craps at the table, you know. This has been a big gamble and a big risk to head into health reform. But it's been very exciting too. I mean, there's the rush of it, but there's also the utter importance of it all. And one of the things one of the parents mentioned earlier today in one of the workshops I was in, no it was a Title V Director that parents are really good at complaining, we're really good at stepping up to say, this is where the void is, this is where the gaps in services are, but they rarely hear what is good that happens. And so I just wanted to knowledge that all of you in the room here working with Title V, there have been many supports that you've put in place in our states that without those who couldn't be here participating as parents. And I wanted to just give you all a hand in that. That's really important.

And I think his parents come from a place of saying, okay, we know those things are working. We also know we need additional things on top of that really have a quality of life and where we go from there. So, I didn't want to start my talk by saying everything stinks, you know but our healthcare system really isn't set up to support families who have extreme medical needs under their roof. It's really set up for us to live in poverty. And I don't know how many of you in the room would choose that and your lifestyle, but I can tell you the families we serve and work with in Nevada, that's not the choice they want. By and large, they really would like to be in a much better place in their life.

But I just want to backtrack to when the beginning of this discussion of health care reform happened; we were talking on, not on party lines. But on Pacific issues in the health care system, how can we improve what is there? How can we take what's there that works, kind of like what we were talking about with the talk about change yesterday. What is working and what do we build on from there and not just complaining about what isn't working and go in that direction.

So in that spirit, I wanted to share with you the Family Voices healthcare reform platform. Last year when the discussions really started formalizing, our public policy staff and committee decided we really needed to be at the table in a really effective way and come up with a couple of crimes that we wanted to make sure we're not just in this discussion. We know that everything we'd like to see happen

was not going to come to fruition immediately. But we've got to be able to say it because if you don't say it can never get it.

So a couple of the main points I wanted to share include that, we say benefits must be comprehensive, flexible, and continuous to address the unique and special healthcare needs of these children. There really includes the heart and soul of the EPSDT program. Being able to get that early screening diagnosis, getting the treatment immediately, getting referred to specialists you need, and then of course, the other issue that we won't even get into today with health reform is having the specialists there to go to.

Healthcare must be affordable to families. You heard my colleague and dear friend, Nicole, talk about her family, even though they had healthcare insurance available through her husband's employer, couldn't afford to buy into it. That happens with my staff of time in my organization today, not 18 years ago. It is an issue that is continually being addressed.

Pre-existing condition exclusions; we need to eliminate those. The benefits need to include comprehensive services to those pediatric specialists that we need are. And finally, the healthcare system needs to be family centered, community-based coordinated and quality conscious. Every child needs a medical home. I'm preaching to the choir in this room about that. The families need to have access to clear information and to have helped navigating those complex systems of

care. That's where our Family-to-Family Health Information Centers come into play. They are very vital right now 's playing that navigator role, but I think they're going to become that much more valuable as health-care reform manifests itself in whatever form it takes.

So that's my lead in into describing to you, what a Family-to-Family Health Information Center does. I'm sure a lot of you in the room are familiar with it, but I've also spoken with a number of you while I've have been at the conference, who are not that familiar with our day-to-day operations and the value that we have within your state. We provide programs that are run primarily by family members. We have walked down that path we have had to navigate that system on our own and that provides very unique level of support that you're not confined and other programs.

We do traditional information and referral, we help families navigate those systems of care, but we also provide that parent-to-parent peer support. And I know Nicole talked about it in her video that was really the core support that I got with my son 12 years ago. He has Downs Syndrome, and I had no experience with anyone with Downs Syndrome in my life, but I connected up with a parent who was working with our early intervention program and I sat and cried with her for two hours as I just kind of spilled my guts about my fears and my worries and so forth. Without that I wouldn't have been able to walk forward with confidence I

have today and be able to talk to you. And I think that every parent in this room can share that same story on some level.

We train families could be better partners with their children's health care providers, how to prepare for an office visit, how to apply for health care coverage, the basics of just filling out an application. You know, that can be very daunting and very scary. And in families with non-medical community-based resources, you know, support groups and the like.

So all of that -- those are kind of the basic services within each state, but each state really customizes it based on their needs. And I can tell you in our state, Nevada, we've had the good fortune of being in partnership with our Title V program and we've received funding for this year to take over their Children With Special Healthcare Needs Help Line. So that's part of our Family to Family Project. Other states are doing similar things, working with their Title V programs.

So one of the questions that you said to me yesterday, Mike, was you know, what was, what could be? Would we go from here? Well, I want to share with you, my personal story and evolution of healthcare coverage for myself and my family, because I think that's a good illustration. A lot of times we get together and parents are there about their issues with Medicaid, or they talked about some assistance they've gotten through Title V. My family has had private insurance. And that to me is kind of like the elephant in the room that nobody ever brings up.

And I think it's really important to acknowledge, because I think all of you can share a lot of the challenges that I've been through personally.

When my husband and I were first married we had just gotten a new job, we had this great insurance policy, I had been doing all sorts of odd jobs for over a decade. So the only way I got health coverage was to become a student at the University in our town, I took a swimming class so that I can get some dental coverage. I went to Planned Parenthood for a gyno exam and that kind of thing. And so finally, we had this full comprehensive package, and very low deductible you know, we had vision and dental and medical and then soon discovered, we needed a maternity rider on it. So all of that worked out great, it covered a lot, and had an income to cover the other expenses that are associated with out-of-pocket costs and then for a period of time. My husband and I were both consultants, and so we had a private policy, but we went from a very low deductible to extremely high. We had a \$5,000 deductible, major medical, no vision, no dental at that point, but we were very fortunate. We kind of made it through and didn't have any major events happen in our life.

And then toward the end of that coverage, our son was born with Downs Syndrome. He was in **** for a couple of days. The costs again, we still had an income to be able to cover those out-of-pocket expenses, but we were looking at a whole new life.

In the midst of that, my husband was diagnosed with clinical depression. How many in this room are on Zoloft or Prozac or something. All of a sudden, we have preexisting conditions in our household. Right? So, we've done this dance in and out of employer-based insurance and private insurance and we're just at a juncture right now, this month, my husband's COBRA policy that he and my son are on is ending. I have employer-based insurance, but it is no where near as comprehensive as what they had had through his previous employer. And the independent coverage is much less comprehensive. But, my husband also, in addition to his pre-existing condition, last summer had a seizure that resulted in an accident where we discovered he had an infection in his brain and had brain surgery.

He is someone who was in utterly perfect health; it came out of the blue – out of nowhere. It's an example of how in one instant the whole family, you know, your income can go out the window. And we're all just one incident away from that.

Fortunately, he had the comprehensive coverage so that our out-of-pocket expenses were minimal, but now we're facing the application for private insurance that says, in the last six months, have you had a CAT scan? Have you had an MRI? Have you had any special medications? Well, we've had everything. And I'm finding myself sitting there thinking, gosh, is there anywhere we can fudge anything? And we're not going to. And some, you didn't hear that, right?

But those are the kind of challenges we go through day-to-day. And all of you, I think in this room, have experienced some level of that. We also are in the sandwich generation. We had our father-in-law living with us two years ago, and he went through a health crisis and died. And we had to figure out his whole system of care. He was a Vet, so now we've had the experience of electronic health records and thinking, right on. Those elements I think are all really important.

So, all of that was just to share with you the importance of providing personal stories. And I think we're, again, preaching to the choir to a bit. But I think figuring out who it is that you're talking to, those of you who are going to go up on Capitol Hill today, there are many stories that you can take with you that you might not even know you have that you can share. And certainly those of you who have come here with family delegates, or have a family member on your team that are going, please be sure to let them know the importance of that peer support through our Parent-to-Parent Programs, our family support programs, and our Family-to-Family Health Information Centers. We're going to be here in the long haul to help families navigate through whatever health reform happens. And we are at a juncture, at the end of May, where the funding for the Family-to-Family Healthcare Information Centers is ending and there is a provision in the Senate bill that would fund us for another three years. So, if any of you can put a plug in for that, we're also happy to put the plug in for the block grant for you. That's what our partnership is all about, right? Right. Okay. Thank you.

Bob Hall: Wow, how do you follow that? My goodness. What a compelling story. Thank you so much for sharing that. It's hopefully what pediatricians are hearing from families in terms of what they need and how they can be of help all across the country. So, gosh, who wouldn't vote to move health reform as a result of that story?

Again, I'm Bob Hall with the Academy of Pediatrics. I often talk to lots of doctors about these issues and so I often start out these meetings saying, hi, my name is Bob and I'm a recovering lawyer. I'm not nearly as funny as Brent. But, essentially from the academy's perspective, there are a number of issues that we sort of recognize and this wasn't going to be about kids when we started off. Starting off with this last year, we were lucky enough to get the Children's Health Insurance Program reauthorized, and additionally there was a lot of stuff in the stimulus that really didn't go to help Medicaid programs, fund health IT systems, etc., but even before that time, we could kind of tell that one of these candidates might be very interested in health reform. The other might be interested I health reform as well, and we knew it was going to be an issue in the future. So, between 2007-2008, we sent out a survey to pediatricians, **** to be valid. It's called the Periodic Survey. We do it periodically. And this one was number 72. And we asked them, so, what do you guys care about in health reform? What do pediatricians want to see as a result of health reform? What does it mean?

And generally, we got a pretty good feeling that a lot of folks really cared about getting kids health insurance. Pediatricians, I think it's 96.6% of pediatricians valued that very highly, and I don't know who the 3.4% are. But, generally, there's a good correlation between health outcomes and having health insurance. And pediatricians know that and they interact with those health insurance systems all the time. So, that was clearly the highest priority for my doctors.

Secondly, they recognized this point that was brought up just a second ago, that kids need different services. The regular "child" in the first year of life is supposed to go to that doctor eight times. That's very different than an adult. And you can burn through that HSA pretty quickly if you have to go over and over again, and if those are not just well child visits – well baby visits.

And the third thing they really recognized was that in order to make the whole system function, you really need to make sure there are enough doctors, and also make sure that payment means something. That those children can get into the door with that card in hand. And so that's really under the roof of access. So, as a result of some of that feedback went to a printer, put in some cute pictures of kids and put together one-pagers. These are all on the APS website if you have any interest, we have a one-pager that tries to distill – I hope not many of you all have had to read academy policy, but every single academy policy takes like two years to put out there, a hundred pediatricians have their hand in it. It's very complicated. Of course, Capital Hill likes things in three bullets. And so

handing them a big policy statement isn't as effective as having a one-pager. And so if you go to the APS website, you can find a one-pager on pretty much on any issues that might have come up and how they might relate to kids.

We tried to plug in our advocacy on kids with this population in mind, with kids of special healthcare needs in mind because so much of the discussion is about costs and how can we contain costs. And kids just don't cost that much generally, except for this population. This is really the population they are thinking about when they're thinking about how do we make sure that people get what they need.

So, to give an update on where we are from the academy's perspective, there are two points I would like to make under each of those coverage benefits and access, the CBA. In terms of coverage, the Senate bill does keep the CHP Program; it actually funds it a little bit longer. Even after the exchange stands up, or exchanges I guess I should say, stands up, CHP continues. And that's really important because essentially kids with special healthcare needs who are in CHP it's oftentimes a very good benefit package in CHP and can even be an expansion of EPSDT. In states that have decided to take up that option and use those dollars to fund their Medicaid program. But CHP is a good program and it's really important that it succeed.

There was a little bit of a pushback, a push and pull within the kids community about, well does CHP make sense when we have something that looks like it called these exchanges? Is it good for families to be all in the same coverage? If so, you don't have to pay two deductibles. Normally, CHP has such a good cost sharing benefit to those families that you're basically paying a penny or two pennies out-of-pocket for every single dollar of health services that you use. So the cost sharing is really a pretty dispositive factor to make sure that CHP continues for families to not be burdened by their health costs. So, coverage, we're okay. We did okay in CHP. Again, CHP is important. CHP has in fact funded Medicaid more than it funded CHP. We won't talk about that.

But beyond that, we are very concerned about the Senate bill's coverage of immigrant children. If you are a family who has one person who can't provide documentation, it appears that you may be barred from the exchange going forward during the exchanges. That's a big problem for a lot of kids because there are families who don't have all – not everybody has documentation. And so certainly from the academy's perspective, when we say, all children should have health insurance, we mean all children should have health insurance. And unfortunately, I just don't think we achieved that with these bills. We still have work to do obviously.

Beyond that, in terms of benefits, we did pretty well in this area. We got a really pretty juicy benefits package for these kids in these exchange plans. Pretty much

everything you mentioned. Kids would get vision coverage, they would get dental coverage, they would get habilitative services, not just rehabilitative services, but habilitative services. If you go down the line of what we were able to achieve for kids, it's a lot of what's in EPSDT. And certainly not some of the really great things under the treatment side, not transportation not a few other things, but generally, it's a pretty good benefit package that recognizes that children are fundamentally different.

The thing that nobody has really talked about too much is really one of the early deliverables. If you've had the unfortunate experience of having to read these bills, you know that there's these large sections at the beginning that say, hey, we're raising a flag and saying how good these bills are. One of the early deliverables is actually; every child would receive all Bright Future Services with no co-pay, a huge step forward in terms of prevention. So, thank you Health Committee, thank you some pediatric advocates. I will mention Chris Dodd's name, he did an incredible job inputting that forward, Senator Harkin as well. So, that's something nobody really talks about too much, but a huge step forward. I think that's if you have an ARISSA plan, that's certainly if you have a state-regulated plan and it's certainly if you have a state public plan. You would get all Bright Future Services. So, big step forward. We've got to work to implement that.

In terms of the final bullet on access, like I said, it's really a workforce question and a payment question. Workforce is actually really good in the Senate bill. It's

actually better from the **** perspective than the House bill. There is \$30 million per year for I believe 10 years to help pay back loans for pediatric sub specialists. If you decide to go into pediatric sub specialty, you will get \$35,000 per year to help pay back your loans, which is a big inducement to get folks in because we recognize that there is a serious access problem to primary care, and that's certainly what Massachusetts experienced once they expanded coverage. But once those kids are really sick, it's very difficult to get in to see the pediatric sub specialist. And so we need more. So, a good recognition of that, and that was not in the House bill.

There's also a good primary care workforce provisions, but I wanted to highlight that also. There's some mental health professionals who are encouraged to continue in pediatrics sub specialty as well.

But the final think under access is payment. And the Senate really falls down on this issue. There is nothing essentially on Medicaid payment in the Senate bill. And the state-by-state dance that happens that we feel a little burdened in comparison to some of our other physician colleagues, we have 57 fights that occur all across the country – excuse me, negotiations that occur all across the country. Whereas, the Medicare system, you've got one lever at the federal government you have to pull. So, it's a lot different for pediatricians and other Medicaid providers in that negotiation that occurs.

So, that's very different than the House bill. The House bill had this wonderful section, 1721, which would have actually raised service payments for what's called "evaluation and management codes," not procedure-based codes, but sort of the cognitive services. Those would have been actually raised to 100% of Medicare over a period of years and the important thing about that is it was going to be federally funded. The states can't afford it right now. It's very difficult right now. We understand the straits that so many states are in. You're programs are probably feeling that all across the country. It's a lot to ask states to pick up those rates, of course, we think they should all be high, but at the same time, we understand the budget crunches that folks are going through.

We're hopeful that as a result of the summit, something actually did come out of the summit at Blair House this last Thursday. There was a letter that the President put forward. He put forward four ideas that were raised by Republicans that he was very interested in pursuing. And the third idea was actually an increase in Medicaid payment. So, we're very hopeful that that's going to be substantive and not just window dressing and address this real concern that we have that we are adding all of these new populations to Medicaid. They get a much higher F-Nap, 100%, then 95% then 90%. Ten years out, after we pass this bill, you look at who gets what, kids get this 23% plus the F-Nap currently in CHP for CHP coverage. Adults who are newly in Medicaid get 90% F-Nap, and then you've got the traditional Medicaid populations who get 60%. If I'm a state, who am I going to cut? It's going to be very clear that I'm going to cut the folks that I

get less of a federal support for. So, we're setting up an incentive to really devalue kids and nursing homes and other traditional Medicaid populations in comparison to some of these new enrollees. But we're cognizant of the need that states have. We're hopeful that we see some real money on the table to try to raise some of these rates and really provide access to those kids once they have that card.

So, that's where we're coming from at this point. We're not done yet. We're activated and very interested in seeing this finish because this has been a long time for CHP **** to this and we could all use a break, and then we get to implement it, right? So, looking forward.

STEPHANIE BIRCH: Very good. Very good. Michael, have you --?

MICHAEL FRASER: Great. Well building on Bob's comments, when we planned our program, we really thought we would be talking about implementing health reform at this session. And it really has been a wild ride. I haven't ridden roller coaster like this in D.C. ever. And it's great to have you both on the panel to really amplify some of our messages and share yours. We appreciate that. Before I just make a few quick remarks, I hope you're thinking of questions because we really do want you to have a chance to ask and comment on this issue.

I want to just give my special recognition to our policy team at AMCHP. We have two and a-half FTE's that we use for policy that I think does the work, I think, of 25 led by Brent and Josh Brown, our Appropriations Associate, and Michelle Oletta. And I think what's exciting about our policy team is not only are we interested in the coverage issues and the provider issues the family issues and what this means, but also, how do we build state public health capacity that cross cuts like your programs do, a number of different problematic areas within the state health department.

And so, the two things I would touch on real quickly before we open it up to conversation is there are some provision in the Senate bill that are extremely supportive of public health and of state public health departments. The two I would point to in particular is, number one on the list here, which is a prevention in public health fund which as soon as the bill is passed would let about \$100 million to states, locals, and other entities to really build on prevention programs in your state now. And while that may not be specifically Title V, and it may not be specifically MCH, part of what we've been talking about last fall and into this year is the need to reach out across different agencies – across different divisions within your agencies to take advantage of some of this new money and make sure that MCH is at the table.

We know that chronic disease is going to be a very, very big piece of any – chronic disease prevention, and it is going to be a very big piece of any health

reform legislation moving forward. And MCH should be at the table in those conversations.

Lastly, I'll just mention that bullet number seven relates to the conversation we had this morning, which is on home visitation and the Maternal Infant and Early Childhood Home Visitation Program that's in the Senate bill really identifies Title V as the locust for building home visitation programs across the country and acknowledges the co-leadership of both HRSA and ACF in implementation. And I think there's a lot of potential there for maternal and child health programs. And we really, really need to pay attention to that and hopefully that will be the next bit thing for MCH programs moving forward.

So, with that, Stephanie, I'll turn it back to you.

STEPHANIE BIRCH: Very good. So, I think we have the mics live. And I think we'd like to entertain some questions.

LAURA MCALPINE: Hello, my name's Laura McAlpine and I'm with Health Connect One which replicates that community-based Dula program nationally and for those of you who don't know what a Dula is, it's a woman who works with a woman during pregnancy and her family and also at the delivery. It's a critical part of that and then afterwards. And I wanted to give you an image that we're going to share with our Congressional delegation tomorrow when we're on the

Hill that you can all use, and then I do also have a question for Mike and Brent. But, Senator Durbin has been our champion on this program. There's 24 programs in Illinois and he understood the vision of this and is trying to promote it nationally, and there is federal funding inside HRSA for six programs right now nationally. So, we're giving him a t-shirt on Thursday that says, "I'm a Dula for health reform." And we're helping him understand that while the pregnancy has been very long and the gestation period may be more like an elephant than a human, we think transition probably occurred once we lost the 60-seat majority in the Senate, but now it's time for pushing. And as the Dula for health reform, he has got to help get the pushing going. And help get to birth health reform for the country. So feel free to use that in anyway that works for all of you.

But my question for Mike and Brent is that the one place where we see, I mean, there's many places in health reform where potentially the community-based Dula program fits, but one place is the grants to promote the community health workforce. And I didn't see that on your list and I wondered if there was a reason for that or if that's – I know there's so many different pieces inside that 2,074-page document. And actually I think that is a challenge for many of us in the room that we're all sitting, not just looking at your list, but other lists and saying, where do we fit and how, you know is our funding going to be continued to be fragmented, or will health reform be a way in which there is more comprehensive funding brought forward. So, that's kind of my bigger questions as well as the specificity about that particular funding stream.

MIKE FRASER: Sure, I appreciate that. And when we're distilling a document, the lens that we're using is, what is it that our Title V Directors or our Children with Special Healthcare Needs Directors, folks that are working in a state health department should know about first and foremost so that we do the analysis as quickly and as accurately as we can of a 2,000 page bill and distilling that into 22 bullet points, or hopefully fewer. And so there are going to be things that aren't necessarily on that radar screen just because of the other bits and pieces that we think we want to get out to members more critically. Not to diminish the other pieces but because we want to be that place where you go to get information real time about what's going on and it would be very, very specific to your work.

With that said, I think that there's a number of other things in the legislation, the proposed legislation that you should know about. The community health workers is a big piece of that. We don't necessarily track that as closely as other partners, and so part of what our legislative agenda is all about is really, in some ways, a work plan in defining where our two and a-half FTE's and the volunteer leadership that we have is going to be able to spend their time most effectively.

I can tell you right now that no one else in this town, not one other group in this town is going to advocate for Title V. It is not going to be any other group's number one legislative priority; it's probably not going to be any other group's number two, or even number three legislative priorities. And so with that, we

devote a substantial portion of our time to advocacy for Title V MCH block grant services funding. And for that reason, it squeezes all the other things that we couldn't and probably should do if we had more capacity here at AMCHP.

Brent feel free to add, I think we try and leverage resources from all of our partners to get Title V on their list and that's why we're excited about working with the folks in this room that aren't necessarily Title V.

Brent Awig: Right. But as far as the summary goes, we should have a bullet on workforce because there is a lot of exciting provisions in that and that's just my fault. So we'll get that fixed. Specifically, I believe in the Senate Bill, there's also a public health workforce scholarship and loan repayment program that would be very helpful. So there are things in there that are key that I just tried to keep it to four pages. And I wasn't able to fit in – I think there's been additions too, I realized in our description of essential benefits, we didn't make the reference to Bright Futures which is so core and something that we were talking on the Hill with Bob and other friends, and then there was an amendment accepted at the beginning of the debate which puts in a process to create a central Bright Futures for women that would be part of the benefit package. And so, I need to add that. So, that's all by way to say, hopefully you read the caveat we had at the top that it was not comprehensive, so I do apologize because that is a key provision and we will add that as well as some other key provisions. So, appreciate that feedback.

STEPHANIE BIRCH: Thank you. I'll take the question over on the left.

Q: Yes, actually, Mike, in some ways you answered what I already was going to say, but I just have to tell you how critical this information is that you get out to us. And I don't care if it's in a pretty document or not, but the faster you get it out to us the better it is. And I really appreciate it. Many times – I'm from New York State, and many times, I'm the one providing your information up to our governmental affairs to follow up. So, again, I don't care what it looks like, but as soon as you get the information, we really appreciate the way you get it out.

And Brent, you've been – you know, the two of you have just been invaluable to us. So, thank you.

MIKE: Thank you. I could tell you a funny story about that if you'll indulge me.

STEPHANIE BIRCH: I was going to comment that Brent's gotten two ovations today. So.

MIKE: I know and I think they were deserved too. The first week I was at AMCHP, I got an email from a member that I won't name. And she – we hadn't met yet, this was the first email that I got from her. And she emailed me and said – forwarding me something, and said, "This is something that I should have heard

about from AMCHP first.” It was a policy that had to do with Title V that came from another provider organization that she’s a member of. That was three years ago. That was really my call to action, and I think what brought our team together because she was right. There are things going on here that matter to Title V Directors and you should hear about it from us first. And so, sometimes we sent the email three times by mistake. But at least you got it three times instead of zero times. And that’s the kind of thing we want to know from you, and Brent needs to know for his team, and our board needs to know for their look at what we do. Are you hearing about it from us first, and is it useful? So, thank you for that comment. That’s our goal, and we want to continue to meet those needs for information. And it often isn’t pretty, but it is hopefully accurate and that’s our underlying goal.

STEPHANIE BIRCH: Thank you. Question in the middle here.

HILLARY PEABODY: Hi, Hillary Peabody with the National Institute for Healthcare Management here in D.C. and if you’ll excuse me, this might come out a little bit pessimistic. I really appreciate everyone’s optimism here and you know that the reconciliation process is going to work and I think we should be working really hard on that and it does seem like these next few weeks really are those critical weeks, and something’s going to happen whether it’s what we want to happen or what we don’t want to happen. And so, to sort of taking that in stride, I’m curious, realistically, what do you all see happening if what we really want to

happen doesn't happen and here we all are right now, it seems like a good time to at least have that in the back of our minds before we all go back home. What's next?

STEPHANIE BIRCH: Who would like to answer that one?

BRENT AWIG: I think we each do really. Yeah, no, it's a good question.

STEPHANIE BIRCH: Yeah, Bob? You want to start?

BOB FRASER: So, one thing that might be instructive about that is some history. We did go through this about 15 years ago, or 20 years ago. And as a result of that process, we got something called the State Children's Health Insurance Program. So, even though a lot of discussions are not about children on Capitol Hill, kids still pull really well, and there might be some step forward in terms of something along those lines. That's pure conjecture, but that is historical that we did get that program as a result of that change.

I personally, not speaking to the Academy, If they vote next Thursday for the Senate bill we got a bill. We've got a law, as long as President Obama signs it. So, I think that's a concern that a lot of House members have in moving first on passing the Senate that they didn't write that bill, and there are some things in there that they do not like. But if they do pass that bill, we've got a law, even if it

can't do reconciliation. So, that's definitely in a lot of the House members' minds. I think at this point, we're at least publicly declared at least 50 Democratic Senators saying they would move forward if reconciliation, but I think it's not – having worked in the Senate, it's not Senatorial to write a letter saying yes, we're on record in favor of this and House you can hold us to it and what is the enforcement mechanism of a letter, and all of that stuff is up in the air. But I do think that, if this all crumbles, again, if you look at the history of the Clinton Health Reform Plan, if there was an actual security crisis, things can happen. So, the longer you delay these processes, the more chance there is that something like that happens; there could be something else that could occur. I cannot tell you jot and tittle what that would be, but certainly we would be pushing pretty hard to get as many things for children and pregnant women as we possibly could.

Stephanie Birch: Good. Brent, do you –

BRENT AWIG: I don't know exactly how to answer that except to say, the reason we're optimistic is because Mike made very clear when he took the helm at AMCHP he wasn't going to hire any cynics or pessimists, that we would contract out for that, and I apologize to anybody, but I've contracted ****. But I think from the beginning it was clear that there's a million places where it could fall apart, but there's a political argument to be made that we can't wait, that doing nothing is worse than passing an imperfect bill and it's going to come down to political calculation and a very close partisan vote, which will have implications for how

enthusiastically this is implemented at the state level and I think we can talk about that where we are anticipating in thinking that through.

But if it fails, I think it would be unlikely that any large scale reform would be able to happen in the next few months before the elections in this environment. I will share with you something that we should keep in side this room, which is there is clearly a lot of interest in home visiting from the White House on down, and it's clearly a part of the bill. And our Plan A is let's get a health reform bill with that investment in home visiting in there.

We would never say publicly that the Plan B is, say, let's find another way to pass a home visiting program because we don't want to signal that Plan A – that no going with Plan A is an option right now. But if that were the case. I think you saw a strong coalition of partners on stage this morning that we would be interested in working with to see if there is a way to pick out some of the important pieces and get that investment through another vehicle, but we don't want to say that publicly until we now for sure that that has to be on the table. So that's one thought.

STEPHANIE BIRCH: Good job. Marsha?

MARCIA O'MALLEY: I think if things don't pass the way we think they are, there are going to be a lot of family members are going to speak up about it. And

they're going to be very vocal about what's not working and what needs to be changed and continue to fight the fight. I don't know if there's anything else that I could share beyond that, but that is just the way we are.

STEPHANIE BIRCH: Sure. Good. Joanne.

JOANNE DODSON: Hi, I'm Joanne Dodson, the Title V Director in Montana and Brent actually got me started right here so that I got the idea. So one of the things, it's great to have partners talking about is what we all recognize with Family to Family coverage and workforce, I was going to take the opportunity just to, what's your perception from your constituencies are, Bob and Marcia, about the role of home visiting with the groups you're working with. I think we sometimes kind of treated separately, and I just think it would be nice to hear what your thoughts are about how home visiting fits.

MARCIA O'MALLEY: Oh, I think it's critical. I mean, I could talk from personal experience, I mean, I skipped over this part of my life story, because it didn't seem imperative to the health reform piece, but my first child died shortly before he turned four, but he was born a few weeks premature in its bid actually more time in the **** than my son who has Down's Syndrome. So I had five days experience with that. That's enough. One day is enough, if any of you have done that. But we had the home visiting nurse and she admitted after a couple of

months, she said, "I know you don't really need me but I really enjoy coming to talk to you."

But she provided me with all kinds of great information on child development and all of the new research on brain development is coming out at that point and she had some neat resources to share. And I think it's just critical. I mean, there are a couple of issues; we've got families who wind up living in isolation for a while. Many of them have their children in a hospital setting and may be living in a community that's got there on for months on end. Many of them are from out of state here in Nevada, similar to Montana, you have very limited resources. So a lot of our folks wind up in California and some medical centers there or in Primary Children's in Utah. So having that kind of support come to your home is very similar in nature to the support that we get with early intervention, where the supports are given in the natural environment. And if your child is not in a daycare setting and you have them at home, the services come to you there.

So I just think that it's critical. I think in many more ways than a family that is raising a typical developing child because you are just a situation where it's so new. And so on down any level is support on that basis is critical.

BRENT AWIG: And I would say, I don't know how many of you have read the TRIPIA, The **** Insurance Premiere Information Act,

Title IV who will within that Bill is a quality measure section that really focuses on pediatric quality measurements. I think the Academy is strongly in favor of making policy in the same way that that quality measure section was out there. We need to be making sure that what we're doing sense from a data-driven perspective and what interventions we are doing, how are they helping children etc.? It would be really nice to know if our whole other range of policy options that are out there and how they impact of those children are receiving and the outcomes that occur. It seems. It seems pretty clear to me from my reading of whatever data I've been exposed to that the home visitation programs work really well and has really strong data to support that they help these kids and these families. And so that's a really great way, it seems to us, to be making policy is to be testing things and making sure they were and then putting the money where that information is there and that hopefully gets past some of the political mumbo-jumbo that's going on around health reform. And really can either use of tax dollars.

STEPHANIE BIRCH: I'll take a question from the front.

MARILYN HERTZLE: Thank you. I'm Marilyn Hertzle from Oregon, with the Children Special Health Care Needs Program. Just a commentary that comes to mind based on the last question, which is, I hope your Plan C is home visiting universally available to all families as your long-term vision in our country. It may have been enjoying my desert. Too much and I may have missed the

commentary but could you comment our youth with special health care needs as we have this wave of young adults coming down the pipeline with high, high cost needs. What we can expect out of the legislation for them?

BRENT AWIG: I can take that first. I think there are several pieces. First is the affordable coverage that guarantees issue even with pre-existing conditions. So having the Medicaid expansion as the base, the preservation of CHP, the strong benefit package there, and then access to an exchange with affordability credits that's the foundation of the health reform bills and their approach to expanding access. But then particularly in those insurance reforms I think are a lot of key critical provisions affecting children with special needs.

Again, the pre-existing exclusion outlawing that is the base. But also limits on out-of-pocket expenditures and an annual cap and the lifetime cap, both of those I think are of key importance. So, those are kind of from the coverage piece and benefits. Again, I think Sarah framed this in her talk on Sunday night. This is not the benefit package that all of us would write. It's not perfect, but it's pretty darned good. Having the reference to Bright Futures and having debilitating care, I think there's areas that it could be improved and that's maybe where we look down the road is what improvements it would need and using family stories of how it is and isn't working is going to be crucial. But that's kind of on the benefits piece.

On care coordination, we didn't spend a lot of time, but there steps toward that with Medical Home, I think again, probably the House had more explicit resources to do state demonstrations on Medical Home the senate has some language there. I think that bob can speak probably more to that, where the differences are, but they talk about moving the systems to a more of a team approach in community-oriented care. The piece on the back, the state grants to promote community health teams, number 18, I think that would help with the care coordination model expanding that.

And then finally, and to note importantly, number two, that the Senate bill does include the restoration to the Family-to-Family Health Information Center funding for a three-year period. So, those things together. And maybe we didn't do a good job in highlighting those as Children with Special Healthcare Needs components in here, but I think all of those things taken together will move us steps forward from where we are now. Again, it's not going to create a perfect health system that we would all design, but those are all things that will hopefully move us forward in a better direction.

BOB FRAZER: I'm not sure I would really add anything to that. I think that actually, number 15, the bullet 15 here weighs it out quite well. The other thing I would encourage us all to work on as time goes by, is if you look at the essential health benefits. You know, we have that catch all pediatric services. And so I would love to define that to age 85 if we could figure that some way through the

regulatory process to make that meaty. I know that my pediatricians have questions at hand off. I mean, who in the adult provider community deals with this and what I understand is that some pediatricians actually hand off to gerontologists because they're really very adept with dealing with multiple chronic conditions and sort of the stuff that kids with special healthcare needs are going through. So, it's an imperfect model and I don't think the health care reform bill can solve every problem, but it's one that I think we do really have to look at.

MARILYN HERTZLE: My concern is that we can end up with many young adults that we supported into their young adulthood who will be impoverished and/or their families will continue to pick up that. So thanks very much.

BRENT AWIG: There is a provision, and I can't remember who put it in but I believe that it will allow children to stay on their parents' plan to age 26. And so in those crucial years where people are coming out of college, maybe taken a job that doesn't offer strong insurance the they'd be able to stay on their parents' plan and that would provide that continuity throughout adolescent transition for special healthcare needs into the adult care system.

STEPHANIE BIRCH: Good. Good. Go ahead.

DIANE ZEFFLEY: Diane Zeffley from State of Arizona, March of Dimes. I just have a quick question for you, first a comment. I just found out that our

legislature has decided to cut the ASCHP program, leaving about 47,000 kids without health insurance. So, we're unfortunately the first in the nation to decide to do that because we can't afford the quarter on the dollar with the F-MAP. Do you have any idea if any other states are going to follow suit on this and will the federal healthcare reform bill address this at all?

BOB FRAZER: I think we have heard antidotally we have heard of states that are making those kinds of decisions; it's unfortunate to hear that that actually happened. Do you have any thing to add on to that?

BRENT AWIG: Yeah, I think you know that there has been some states that have actually gone forward and then come back from the brink on their cuts to AMCHP. This was one of the issues that the kid's community was really wrestling with. CHP is a block grant structure, and so states really do have to figure out how to use that block grant money and it's not from, you know some of the academies I've seen the most perfect structure of what we would want to see for kids in terms of an entitlement or in terms of other things. So, I would say that the exchange coverage is an entitlement; people don't talk about that too much. Biden actually said that at the Blair House, which I was really surprised he actually said it. But you are essentially entitled to money to help you buy coverage in the exchange. So, there's some good components in that.

We're going to have a hard budget time I think over these next two years and states, I can't even imagine what you guys are wrestling with and going through. Health reform does not include, it appears at this point the F-MAP increases, or the extension of the stimulus funding. We've got to make sure that is happening. I would say certainly from the academy's perspective, we are hearing all across the country of provider cuts in payment. So I just think there is a lot of different states are being forced to do in order to balance their budgets and it's really unfortunate for those Arizona kids. And I don't think it's going to be the only place that that happens to.

STEPHANIE BIRCH: Another question?

DIXIE MORGEES: Hi, my name is Dixie Morgees; I'm with Healthy Start Region IV, Florida. I just wanted to ask, and it kind of piggybacks on the previous question. How important is the maintenance of effort for each state under this proposed bill. When we talked to legislators, whether it's at the federal level or the state level, I think it's really imperative that we talk to them about the maintenance of efforts that these kinds of things don't happen in the state, and we make a commitment to draw down the federal dollars and to put forth the maintenance of effort at the statewide level. So, I didn't know if you could address that. How this bill addresses maintenance of effort for each state?

BOB FRAZER: Well, there's nothing specific I can say about what's in this bill addressing that. I think the issue of maintenance of effort, specific to the Title V Bock Grant Maternal and Child Health Services Block Grant is one that our board has begun to discuss. We're hearing from several states that the unfortunate reality is that maintaining even the block grant match is a challenge. And I think we need to come up in working with the bureau and partners at the bureau with ways to help states figure out what maintenance of effort really looks like and maybe visit with some states that over-match to figure out how that can work and provide more guidance to states, peer-to-peer with this particular issue related to the block grant. Now, in terms of other maintenance of effort, I don't know if you guys want to try that one, but –

BRENT AWIG: I mean, is it specific to Medicaid or all health programs?

DIXIE MORGEES: All health programs.

BRENT AWIG: Yeah, specific to Medicaid, it is pretty clear that states – it's a federal expansion to 133% of poverty and in order to help the states pay for that in the early years of the expansion, 2014-15, I think the President's proposal is that the federal government covers 100% of that cost to the states and then it ramps down a little bit after that and that's been a lot of the dialogue between the Governors and the Hill and the White House is even if it's a great deal, if the state is running a deficit, the state can't borrow the money even if it only has to

borrow \$1.00 to make the match, it doesn't have the capacity to do that. And that's just been a very sensitive dialogue and discussion, but it is clear. It's a federal expansion to 133% of poverty for all population, it's no longer categorical. And so yeah, the states would be expected – and then the nuance there is, the federal money would only cover newly eligible populations, and so we know there are millions of people out there, millions of kids who are eligible for Medicaid but not enrolled, they're not going to get that enhanced match, that's at the standard match and so that's an additional burden on the states and believe me, the governors are very concerned about that. It's something that has been termed the Woodwork Effect. It's a mandate now that everyone has insurance, those who are already eligible for public programs, but not enrolled will have a stronger incentive to become enrolled, and the states will bear a larger share of that maintenance of effort, or that Medicaid match moving forward.

And again, I think this is just to be clear **** that we know are core and crucial to MCH populations, that if Medicaid is paying for half of the births in the country and is covering millions and millions of kids, more kids than CHP, that program is essential and yet, so we understand that and at the same time, it's an area of policy where we can argue what a good policy is, but the politics for us as I say, the association are to defer to the Governors to lead that and not be off message in what they're concerns are and so we are very careful there.

STEPHANIE BIRCH: Okay.

DIXIE MORGEES: Thank you, we all need to be political animals. We need to go out there and fight for our kids. Thank you.