

AMCHP Annual Conference, 2010

Moving Ahead Together:

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

Opening Plenary Session:

Welcome and MacQueen Memorial Lecture

March 6-10, 2010

Nan Streeter: ...mom and I live in Utah. I am a mom of five children, two of which have passed away had some significant health care needs and in my (Inaudible) now because my children meant so much to me I'm a family advocate for our Title V Bureau of children with special health care needs. 23 years ago I had my first son and healthy, beautiful, bouncing boy. I was new, young mom and started noticing that he was getting a lot more of the colds than what my friends the same age were experiencing with their newborns and with every cold he got he would lose a lot of his muscle movement. He wasn't kicking as much and such and so he was admitted to our Children's Hospital for various tests and by about six months of age he had another episode that made it so that he was put on a ventilator and they were not able to wean him off and so that began our journey of what is going on with this beautiful little boy. Ended up being a very rare dystrophy. And but we didn't find out the diagnosis for quite some time since it was so rare. We ended up having to apply for Medicaid to help with some of the health care costs because he was in the pediatric intensive care unit for almost nine months and due to the fact that he was not able to be weaned and not...had no diagnosis at the time and so we had no other choice but to qualify at that point and we were a young

family just starting out anyways and to...in a little apartment and such and so we were...you know we were growing and we were learning along the way. We were released from the hospital to home and due to it being 23 years ago the options given to us at that point were you know yeah you can take him home, loving, he was medically fragile so we thought that his life would be shortened quite a bit. They gave us a prognosis of maybe two years so we chose to go home with him. We were the only caregivers. Now we have some waivers and such that help families like mine have some skilled nursing in the home to help the families. At that point in time we didn't have it so we just did what we needed to do. My husband ended up working a graveyard shift so I could take care of him throughout the night and such and then he would come home and sleep and I would go to work for four hours in the morning. You know for us that became our typical life. But the problem was that we were always...we never got an easy answer to what the questions were that we have such as if we were able to take a raise that would disqualify us for the Medicaid piece of it which for us we had a home ventilator, we had...you know in and out of the hospital so we really needed the health care coverage and we were trapped into a system of poverty at the time of our lives when we really should have been experiencing continuing to learn, climb the corporate ladder...like you're taught in high school. And you start recognizing that the things that you thought were important before are so so little....it's those accomplishments they make. Even if it's for my middle son Brighton, it was walking ten steps and I will hold onto that forever and you know I have a community of providers and professionals that helped us get to that achievement. It wasn't that he was going to become an astronaut one day which is what he really wanted to do but he also said I want to walk past my

principal's office with my class once, so for me because I'm not fortunate to be able to have them with me now but their lives meant a lot and they were here and so...yeah and so that's what I want to share with others is I can't take away their pain in this and sometimes I can't even fix the solution. It may be that we can't get them qualified for some health care right at that particular point. We've come so far in our system in some senses as far as medical home and the coordination of care and all of that but I also work harder now on trying to look at Medicaid buy-ins for families and any type of health care coverage for families due to the fact that like I said before I can't take away what they will experience as far as pain and the roller coaster ride they'll be on but if I can do anything at making sure that there was a service available due to the voices of my children and my health, my family then I feel like we were...our lives are truly meant to be to change something.

(Applause)

Good evening. That was inspiring and it gives me Goosebumps. For those of you who don't know my face. I'm not Phyllis Sloyer. For those of you who do know my face, I'm not Phyllis Sloyer. So will the real Phyllis Sloyer please stand up? Do you remember that TV show? I can't even remember what it was called now. Phyllis unfortunately is not able to be with us for the conference. She had some surgery and had some complications and is not able to travel. She is doing well. She's home. And we talked to her on the phone yesterday and she was really...you could tell...and for those of you who know Phyllis you know her heart is in AMCHP and she was really sorry to miss the

conference. So before we go on if you could take just a moment to send good wishes to Phyllis for a speedy recovery. Thank you. I know Phyllis has been so grateful for all the cards and emails and calls that she's received and so your wishes will help her speed up the recovery so thank you very much.

So I think we have a really exciting conference this year. So here we are in 2010 and we have all kinds of fun things going on. So I want to tell you that this, the attendance this year is the highest attendance that we've had since 2003. (Applause) And I think what that says because we all know that budgets are tight and travel restrictions are in place, it tells us that all of you are very committed. We know you are anyway, but for all of you to be able to come to this conference and join us in working towards the health of moms and kids sends a tremendous message. So I want to comment Gina Paulamoney fortunately is from Utah and is a very active member of our Title V team. And as she says you know we have to keep working. We have to keep working for moms and kids and kids with special health care needs because that's what we're all about. We need to; during the conference we have a chance to reaffirm our dedication, our commitment, our enthusiasm to improve the health of our nation's mothers and children. And I don't know about you but I know every time I leave an AMCHP conference, I come away inspired, energized and invigorated and with full of new ideas. And I think you're going to experience that over the next couple of days so... so the title of the conference is "Moving Ahead Together: Celebrating the Legacy and Sharing the Future of MCH" . You know it's been really exciting here in Washington, not that I live here of course, but to hear all the things that are going on in D.C. to think that the President, in his budget

added 11 million dollars for MCH is remarkable. (Applause) This if passed, will be the first increase that we've seen in Title V in seven years. So it's a long time coming and hopefully it will come. Can you also believe that we have legislation that is supporting or supportive of MCH public health programs in terms of home visiting, in terms of prevention, that's what we're about is prevention. And so it looks like with some of the bills that are before Congress that we will have some funding for home visiting and other prevention programs that we know are so important for our moms and our kids. I want to thank all of you for your commitment by being here, but to thank all of you whatever your role for your commitment to moms and kids throughout this past year and your support of AMCHP and its efforts throughout the year. I think that the attendance speaks for itself in terms of the status that AMCHP has among the MCH community. We want to continue working with our partners because we can't do this alone as everybody knows and we'd like to increase our partnerships or strengthen our partnerships and we've certainly have done a lot of work in that area. I'm just thrilled to be a part of AMCHP. I'm thrilled to be the Past President. It just dawned on me I forgot to introduce myself. That's right I said I wasn't Phyllis Sloyer now you have to guess who I am. Sorry about that. I am Nan Streeter. I am the Past President of the Board of Directors for AMCHP. I'm also the Title V director in Utah, so for those of you who don't know my face now you know who I am. Anyway I'm just thrilled to be part of this organization. I've seen it grow so much and you know I was listening before we started the meeting and the enthusiasm the energy, the talking is just phenomenal and I think that's what we're all about and we need to take that energy home and apply it to our everyday work. So I hope that you're as excited as I am about all the energy, all the moving forward, moving

ahead that we have seen over this past year and we will continue to see in the future.

So I'd like to turn the mike over to Dr. Fraser, Michael Fraser, who is our CEO of AMCHP and he has some remarks. (Applause)

MICHAEL FRASER: Well good evening, thank you, Nan. I was going to say thanks, Phyllis, but thank you, Nan. I'd like to ask the AMCHP board, our staff and any committee members to please stand and be recognized for their contributions to AMCHP over the past year. Would you all mind standing for me, please? (Applause). Thank you so much for all that you do on behalf of our nation's moms, kinds, fathers, and families. And I'd also like to recognize the sponsors of tonight's program two friends that I've gotten to know well over the past couple years from a firm called Go Beyond out of Florida, both Alan and Jason Stamm, I'd like to ask you to stand. The Stamm's to stand and be recognized. Thank you for your support.

Well, my job is to welcome you and tell you we have a great program planned for you. I have in my notes to welcome you to Washington. That's almost true. We're in South, South, South Washington, or North, North, North Maryland, you're actually in the State of Maryland here, we're right on the border but welcome to our nation's capitol area on behalf of AMCHP our staff and our board. We have 704 people registered for this conference, which is fantastic. Hopefully they won't all show up at the same time because we'll be tight, but it's a good problem to have and I think it shows just how dedicated you all are to the topic and to the work that we are all here to do and also to remind you that we have our colleagues at AUCD and Lend directors are meeting with

us and the National Birth Defects Prevention Network are also meeting with us so we have time tomorrow night to party together in the exhibit hall and share business cards and share stories.

This year we are recognizing the 75th anniversary of Title V and I'd like to invite anybody who was there on October 14, 1935 to stand. All right, just kidding, just kidding. I think a couple people here actually were....hahaha...the banners that we have here are provided by a partner called the Every Child Matters Fund and they recognize the 100 years of contributions that presidents have made to children in the United States. They are a non-partisan group and so you'll see a cast of characters surrounding us that represent the legacy of children's commitment...sorry President's commitment to children including the creation of the social security act of which Title V is a part, signed on August 14, 1935 by President Franklin Delano Roosevelt. Lots to celebrate this year as we look to the rich legacy of Title V in the Maternal and Child Health Services block grant. And there's so much to look forward to. We have witnessed again the first significant increase proposed by the President to Title V in a very, very long time. Well deserved and obviously we'd like to see that number bumped up. We can not get that appropriations alone we need your help this week and the week's to come to remind congress that the President proposes and the congress disposes. The President has the power of the pen and congress has power of the purse. And in this very, very tight budget year lots of groups are going to be asking that same ask. So please, please, please, help us make this happen this year. We are so excited for the President's

leadership on this issue and for all the work that we've done and you've done to make this possible.

Please take the time while you're here on Tuesday, Wednesday, tomorrow you have my permission to miss a workshop, a plenary session to go to the hill and echo the message that we are trying to send to congress which is Title V matters, it makes change happen and this is an important investment in our country's future. I also want to celebrate you. We have a great group of folks here and I'd like to ask you to stand if you have been in Maternal and Child Health for longer than five years would you mind standing. Good group. Now stay standing if you've been in Maternal and Child Health for ten years or longer. Okay not a lot of people sat down. Stay standing if you've been in Maternal and Child Health for 20 years or longer. Fantastic. Stay standing if you've been in Maternal and Child Health for 30 years or longer. Lita how is that possible? These are our seasoned, not our old, our seasoned veterans. We're looking to them for guidance. Congratulations, thank you for everything that you've done. (Applause) And I'd like to especially recognize a friend and colleague that I've learned to really enjoy visiting with who unfortunately is retiring this year. Our friend Dr. Richard Nugent from the Arkansas Department of Health who spent 35 years in his career on behalf of MCH and 18 of those in Arkansas. Dick would you mind standing so we can recognize you. Congratulations. (Applause) We have a great group of alumni and we're going to keep in touch with you whether you like it or not you're still going to get Pulse and all those great things that we send just make sure I get your new email address, okay? Thank you for being with us. And folks those are our seasoned veterans and our seasoned

advisors and sage counselors but I'd like to ask those of you who have been in MCH for less than five years to stand. If you've been in MCH for less than five years please stand. Thank you for sticking with us, congratulations. This is our future work force and one that we all care a lot about. We want you to be here in 30 years standing so we can recognize your retirements, too. So please, please stay with us. We're thrilled that you're here with us.

We have a wonderful group of partners and colleagues and supporters here this year. We're going to hear some welcomes from the health resources and services administration and the Centers for Disease Control and Prevention, a few of the agencies that are most significant in our work in the states and our work at AMCHP and I'd like to now have Dr. Mary Wakefield come to the stage to deliver a few remarks on behalf of her agency. Dr. Wakefield is the administrator of the Health Resources and Services Administration and to welcome you Dr. Wakefield we have a unique, at least for me, a unique gift to share with you if you can accept it. Our colleagues in Hawaii brought a lei with them and I'm going to give you an Aloha welcome lei and ask Ileana to help me with this one if you're anywhere nearby Ileana. There she is. So please join me in welcoming Dr. Mary Wakefield the administrator of HRSA. (Applause) I think I'm supposed to kiss you.

MARY WAKEFIELD: In my dreams, Michael. I hope you don't walk off with any of my remarks, Michael. Thank you very much, Michael. Thank you for the lei to the Hawaiians and thank you for that nice introduction. And also I want to say Michael,

thank you very much for your leadership associated with AMCHP and also for your partnership with the Health Resources and Services Administration. In my almost one year in this position it has been a wonderful tenure and a terrific relationship working with you and AMCHP and so I thank you for that. (Applause) And I also want to thank you of course for inviting me to be with all of you this afternoon. Would that Dr. McQueen could have been here with us this evening. But I know that John McQueen's spirit lives on in AMCHP and also in the hearts of all who've had the privilege of knowing him. His passing really came and comes at a significant almost really a momentous time which I'm glad that he had a bit of a chance to see. Not only are we fast approaching the 75th anniversary of the Maternal and Child Health Program this August but also we're in the midst of one of the largest expansions in the...in a focus on health promotion. Illness prevention, wellness, expanded primary care. One of the largest expansions in those areas in our lifetimes. I'm talking here of course about the Obama administrations commitment to the recovery act, commitment to health care reform, and commitments to the health of America's children. Under this President in just one year we have seen reauthorization and I would say badly needed expansion of the children's health insurance program. For children from low income families, from 7 million kids to 11 million children. And we've witnessed an overall increase of almost 32 million dollars above 2008 levels in MCH funding through HRSA's bureau of Maternal and Child Health for such special needs as autism spectrum disorders, traumatic brain injury and newborn hearing screening. And the 7 million dollars for continued work in a pediatric emergency care applied research network, PECARN and pediatric research in office settings pros. And communities across the nation are now benefitting from 2

billion dollars in recovery act funds for unprecedented expansion and upgrades in the community health center system which serves more than 5 million of the nations most vulnerable children. And it also included funding for 125 new community health center sites. To strengthen access to health care also included was 300 million dollars in recovery act funds that doubles the field strength of the National Health Service Corps by 2011 enabling HRSA to put more than 3000 new primary care clinicians into our most distressed, our most underserved communities by this summer. And recognizing the need to invest in the health care work force this administration has also routed an additional 200 million dollars into expansion grants for health professions programs at colleges and universities nationwide which already are supporting some 14,000 students in primary care training. Of those 200 million dollars, 80 million dollars has been targeted for academic debt relief to students, health professionals and faculty half of them from minority and disadvantaged backgrounds. This particular focus I think is an enormous step forward as work force diversity is one of the biggest challenges that we will face over the next decade. And we know from a long experience that students from disadvantaged backgrounds are more likely to pursue practice in underserved communities. I enumerate all of these programs and there are more of course that we could add to that list as a prelude to a simple question. How much do these ambitious, national projects owe to the longstanding Title V MCH programs that have clearly demonstrated that when federal, state and local governments align their mission and their efforts with committed partners from other sectors very, very important achievements are possible. The investments in the various initiatives that I've just described are based on a belief that the government working with and through the

stewardship of people like those of you in this room can meet what would otherwise seem like almost overwhelming challenges affecting the health of the nation. Clearly it's because of success stories like the early and continuing MCH initiatives that concretely established an emphatic precedent of clinical excellence and administrative excellence, of research credibility and tangible results that we see this ongoing confidence in the additional investments that I just described. Title V is a great example of government at its best working successfully side by side with a host of other committed partners. Title V is the longest standing public health program in America's history. From the outset it supported preventive programs for pregnant mothers, infants and children as well as a wide range of medical services including for those who used to be called crippled children. It paid for doctors, dentists, public health nurses, medical, social workers and nutritionists. Almost as important which is something I'll talk more about in a moment, Title V established protocols and embraced standards for data collection and periodic performance reviews of MCH programs. For evidence based research to inform practice and public policy and collaboration between local state and federal agencies to advance public health goals involving women and children. In the years before Title V passed into law data collection was awesome and spotty at best. In early reports of the National Center for Health Statistics is just one example. We see repeated references to the tremendous difficulty that researchers had in making county level assessments of child health and child morbidity. This much they did know though prior to Title V children and certain impoverished enclaves of this country had as little as 2 in 3 chance in surviving into adulthood.

After 1935 dramatic improvements in social and environmental factors coupled with Title V and other concerted national programs led to a sharp decline in childhood mortality and infant deaths and declining at an average annual rate of 4.3% over the next 15 years. And aggregate youth longevity estimates steadily picked up. From 1965 onward infant mortality dropped even farther by about 70% overall from a high of about 100,000 deaths in the year that President Johnson announced his community health center initiative. Well as you all know by no means have we conquered infant mortality. Indeed it remains one of the most glaring strikes against our national health care system and it is a problem that calls out now for renewed attention and renewed action. (Applause)

Yes, I agree. But that rapid decline that predates us now in infant deaths and improvements in public health standards followed the introduction of Title V which were further spurred along in subsequent decades by other programs like the National Health Service Corps, the community health centers, CHIP and Medicaid. It stands to this day as one of the great triumphs really Title V. One of the great triumphs in America's public health. It also stands as a testament I think to the power of data, performance measures and collaboration. Give the challenges that we now face Title V looms even larger as one of the programs that were so essential to helping to inform a much needed and broader understanding of population based health services. Today of course working across and through agencies it's simply what you do every day if you administer a maternal and child health block grant. It's a necessity to collaborate and work together if you are to leverage MCH funds to improve health care in your state. And after 75 years the record shows how undeniably important these efforts really are. People often depend on you to fill gaps. Gaps in medical care. And they also depend on you for

much more. They seek your help with basic needs like transportation to get them into see a clinician. They need your help with respite care. Even the most dedicated parents like the one we saw and listened to in that video need an afternoon off. When their life is all about being on call 24/7 for children with serious special needs. And people depend on you for more than services. They depend on you to make services work. The same families who get help from the MCH program might benefit from nutrition assistance from WIC or from special education funds. Children in foster care can have access to health care thanks to you. At the federal level these programs live in different silos, in different buildings and even of course on different floors within those buildings, but its really you who bring them together. It's you who perhaps too often build the infrastructure to see that all of those programs critically, importantly connect. This demands a lot from you tracking against 18 national performance measures as well, a statewide needs assessment every five years which as you know we're about time to take again this year. But, I think and I hope you agree, it pays off. MCH has one of the most inclusive reporting systems in the federal government and one of the few that also tells you about results. So you can drive toward the next set of anticipated improvements. Accomplishing all of this takes a lot more than magic. It takes commitment, it takes leadership. In the sometimes contentious debate over health care reform, things like regional collaboratives, and health cooperatives and comparative effectiveness research that might make perfect sense within the MCH community where they've been necessary components of effective programs for many decades all of those things are sometimes seen as untried or as unduly burdensome but how else do we measure results. How do we maximize the reach and impact of limited dollars? Most

importantly how do we know that we're affecting people's lives, improving performance, making our systems more dynamic, more responsive, more efficient? No where are these questions more critical than in the lives of the nation's children. So we've been asking and answering those questions for a long time in Title V. In other words, our predecessors were ahead of their time, back in 1935 and we're still benefitting today from their head start.

Since 2001 is just one example MCH has funded a small quality effort known as PECARN that tests the efficacy of longstanding pediatric practices for an investment of just over 5 million dollars the Maternal Child Health Bureau has leveraged research on prevention and management of acute illnesses and injuries and children at 21 participating hospitals. Among other results this research has led to improved treatment for bronchialitis, a respiratory infection common in infants and a leading cause of their trips to the emergency room. And this research has also led to progress in the treatment of head trauma. In another important area of practice we know that nearly one third of U.S. children age 10 to 17 are overweight or obese. More significantly the incidence of obesity continues to rise from 14.8% of U.S. children in 2003 to 16.4% by 2007. And we know that because the Maternal and Child Health Bureau's national health survey of children's health has been tracking that data for years. MCH programs were among the first to identify excessive rates of obesity across the country through your comprehensive needs assessments. And the programs that you administer are working every day to bring obesity under control. We're going to need to know what you know. What you've been learning as we move that agenda forward. Obesity is now as I think

you know a top priority for this administration particularly among children which is a classic illustration I think of data driving policy. Public perception and social action. The first lady's involvement can only help us in this cause. More broadly imagine if you will a health care system held to the same consistent degree a performance review, data collection and population based analysis across the board. This is the promise that health information technology can help achieve in health care. But already a while ago it was feature of Title V.

The Maternal Child Health Bureau under Dr. Peter Van Dyke's leadership was an early adapter of digital technology and data mining in government which has proven invaluable over the years both in terms of advancing public health goals and buttressing MCH budget justifications. Those two things go hand in hand which is just one more reason that I think we are all fortunate to have someone of Peter's foresight as associate administrator of that effort inside the Health Resources and Services Administration. If anyone from the federal government deserves a round of applause for working tirelessly on behalf of the nation's mothers and children it's Peter. And I'd like you to join me please in thanking him. (Applause) Another key component built right into the maternal child health programs are collaboration and here again is another opportunity for you to demonstrate your leadership. One recent survey for example found that we have lost 11,000 state and local public health staff positions in the recent economic downturn. Severely diminishing our state and local public health agencies. Helping to bridge that gap is a totally revamped role of HRSA's regional offices now designed to act as HRSA's key linkages between our programs and grantees and

others like you on the ground. Under a new associate administrator for regional operations Regan Crump who also happens to be an alumnus of the National Health Service Corps, under his leadership the regional offices at HRSA are working to strengthen connections between our academic health centers, state and local health departments and HRSA's various grantees as well as other key health care stakeholders. In tandem with not only our maternal child health program staff but also with our regional staff I would ask all of you to look for ways to broaden your collaborative efforts, not just among yourselves or through the health centers, but across all health care entities and with interested parties. Its critical if we are to sustain the progress that we've made in the past year, particularly now, particularly in these fiscally challenging times. Finally let me just point out that one reason HRSA's programs, most notably the National Health Service Corps and the health centers have been singled out for such substantial investments under the recovery act and in the reform legislation in the senate is because they have a proven track record. As AMCHP has observed many times and correctly I think these programs work together with and through MCH networks supporting common goals, innovating to solve problems which is one reason that they enjoy such broad based support on both sides of the political aisle today. The health reform legislation now struggling and moving through the congress includes a billion dollars for home visits in the maternal child health account. Well it remains to be seen whether that funding comes to fruition but it still represents an overwhelming vote of confidence in the kinds of work that you do and it represents support for the populations that you, well that all of us really, care deeply about. Despite the early decades of progress made under Title V against the scourge of infant mortality

that I alluded to earlier, we still rank last among developed countries in the percentage of children who die before their first birthday. So the inclusion of such a large component for home visits a practice that you all have proven works, yet again illustrates how data can and should drive policy and drive practice. So in summary, collaboration, commitment, data driven practices, a shared focus, a sharp focus, on performance improvement, a search for efficiencies, meeting people where there needs take us, a willingness to explore new approaches to take risks, that's the legacy of Title V and the Maternal Child Health movement. That's a legacy that we can all move into and build on. And I'm pretty sure that John McQueen would be proud of that and proud of all of you. Thank you very much. (Applause)

MICHAEL FRASER: Thank you Dr. Wakefield, it's such a joy to have a leader who can so fluently describe our issues and is so interested in what we do. Thank you for your leadership. (Applause) And as we had a preview what would our Louisiana friends say, a Lanyap, a teaser, an introduction for Dr. Van Dyke, I'd like to introduce our friend, Peter Van Dyke to the stage to welcome you on behalf of the Maternal and Child Health Bureau of HRSA. Welcome, Peter, we're glad you're here.

PETER VAN DYKE: Thank you, Michael. Well it's great to be here among friends and co-workers. It's great to follow Mary. Perhaps it helps you understand why I have a silly grin on my face, a little quickness in my step. Isn't she great? (Applause) I don't have to travel quite so often because meeting with her is such a trip. (Laughter) Moving ahead together, celebrating a legacy, a moment in history. Someone stood before you as

President of AMCHP 29 years ago to announce a change of agenda for the rest of the AMCHP meeting. We had just been informed the night before, it was last night, 29 years ago that someone from the administration was coming to tell us our MCH program currently operated as only a formula program was being block granted to states. That was the spring of 1981 that someone standing before you was me. Anyone here there. Why don't you stand up? Sally...I saw Bill...Bill...Bill...Deborah and I think John McQueen was...Josie, I don't know if you were there or not you may have been. So there are perhaps a few people that were there. What does he change? We changed the agenda for the program on the spot. We were being told that we were going to gain greater efficiency by block granting programs to states. So you combine all the money in MCH reduce it by 20% and then with a greater efficiency gained by working together in collaboration we provide the same or perhaps more care in a collaboration. Moving ahead together. I found a newsletter from the bureau from just two years after the block grant was instituted and I read it in the spirit of moving ahead together.

Title V of the social security act which was authorized as the MCH program in 1935 was most radically amended in 1981. The omnibus budget reconciliation act of 1981 while not changing the program's focus on services for high risk mothers and kids instituted the new block grant to states which increased the role of states and decreased the role of federal oversight of MCH programs. States were perceived as being in a better position to assess the priority health needs of their women and children and to apply their resources accordingly. The block grant allocation consolidated into a single entry the former grants to states for MCH for crippled children services, for genetics and

hemophilia as well as for the former project grant programs for adolescent pregnancy, lead base paint poisoning prevention and Sudden Infant Death Syndrome. Congress included in the amended Title V a number of safeguards to encourage the continued support of certain service programs in the states and also established a set aside of between 10 and 15% of the funds. These came to be known as the SPRANS program which included research, training, hemophilia diagnosis and treatment, genetic diseases screening counseling and referral, and a general category entitled other special projects which demonstrate and test a variety of approaches intended to improve the delivery of services. Within two months of the enactment of the block granted program to states 52 of the 57 states in jurisdictions had applied and received the new MCH block grant. The State of Vermont was the first to provide the required report of intended expenditures which was then called the application and was the first to receive its award dated October 15, 1981. By July of 1982 all 57 jurisdictions had accepted the grant and were moving to either affect a smooth transition to their expanded role in managing MCH programs. The transition was carried out without major difficulty and with maximum cooperation between the federal and state agencies responsible for Maternal and Child Health. The facility with which the block grant was implemented testifies to the long and positive working relationship which has been developed over the years between federal, state and voluntary agencies, a partner based on dedication to the improvement of health status of America's mothers and children. Moving ahead together celebrating the legacy. We've had a long history. Henry Ford was heard to say coming together is a beginning, keeping together is progress, working together is success. We have a history

of working together; let's continue to work together successfully. Have a great meeting. Thanks very much. Welcome from the MCH Bureau. (Applause)

MICHAEL FRASER: Thank you, Peter, we appreciate your leadership and for joining us this evening to share some thoughts on the history and the future of Title V. It's now my great pleasure to introduce a very important partner to AMCHP and to all of us in the states, the Centers for Disease Control and Prevention. And here to welcome us on behalf of the CDC's new, can we still call him new, director, Tom Frieden is another new director at CDC Dr. Ursula Bauer. Those of you from New York State may know Dr. Bauer because she was previously the chronic disease director in the State of New York and also served in Florida for some time and it's our great pleasure to meet you and welcome you to AMCHP so you too can see and experience the energy and enthusiasm that we have for Maternal and Child Health and the appreciation that we have for the programs that are run by CDC that help improve the lives of women, children, fathers and families across the country. So please join me in welcoming Dr. Bauer to be with us this evening.

(Applause)

URSULA BAUER: Good afternoon and welcome. I'm new to the federal government, new to AMCHP, new to CDC, but I can't think of a better place to be on a Sunday afternoon than here with you. Because our work in chronic disease prevention and health promotion cannot succeed without your dedicated work in maternal and child

health. That connection is clear to us at CDC with the location of our division of reproductive health in the national center for Chronic Disease Prevention and health promotion. It's also clear in our new director's priorities. Dr. Frieden has identified tobacco, nutrition and teen pregnancy as three of the six areas of focus for the agency. Progress in each of these domains improves the health of women of reproductive age, improves preconception health and improves maternal and child health outcomes. Dr. Frieden has also identified surveillance and supporting state and local health departments as core functions of the agency to be strengthened and to be improved. He's created the office of surveillance, epidemiology, and laboratory services and the office of state, tribal, local, and territorial support to work with the centers to advance these functions. Again progress in these areas strengthens your ability to accomplish your goals. We know that chronic disease prevention and health promotion begins before conception and continues through the life course of mothers, infants and children and I hear now fathers and families should be added to that list. Many argue that we cannot address poverty in our country without addressing teen and unwanted pregnancy. The fetal development and early childhood experiences influence coronary heart disease later in life and even reproductive outcomes in the next generation. Breastfeeding is a primary prevention strategy to bring under control the epidemic of obesity and is so important to infant health. Gestational diabetes is a warning for Type II diabetes some years ahead. Safe motherhood also begins before conception with proper nutrition, a healthful lifestyle and a safe environment. It continues with appropriate prenatal care, the prevention of complications and the early and effective treatment of complications. The ideal results are pregnancy at term without

unnecessary interventions, the delivery of a healthy infant and a healthy post partum period in a positive environment that supports the needs of the woman, infant and family. That positive environment and it's sustainability over time are essential to ensure a long and healthy life free from chronic disease and injury and a health next generation free from poor reproductive health outcomes. Many U.S. women enter pregnancy with preventive preexisting risks. Among women of childbearing age 69% do not take folic acid supplements. Nearly half are overweight or obese. 10% have diabetes that could impact the pregnancy if not well managed and during pregnancy 11% of women smoke and 10% consume alcohol. These behaviors contribute to poor birth outcomes and contribute to poor health outcomes later in life. Prenatal smoking remains one of the most common preventable causes of infant mortality and morbidity and is associated with 30% of small for gestational age infants, 10% of pre-term infants and 5% of infant deaths. And when an infant is exposed to second hand smoke there is an increased risk for respiratory tract infections, ear infections and sudden death.

Tobacco control is the topic near and dear to my heart. We must deliver sustained and comprehensive tobacco control efforts in order to reduce smoking rates including among women who are pregnant. Improved nutrition before, during and after pregnancy, during infancy and childhood, throughout the life course and for the whole family is urgently needed to prevent not only poor pregnancy outcomes across generations but heart disease, diabetes and even some cancers. The teen birth rate kicked up recently after a long and steady decline. We must re-double our efforts to ensure that all pregnancies are wanted and our children are beginning life with the

advantages that will allow them to achieve their full potential. The National Center for Chronic Disease Prevention and Health Promotion is working in so many ways to address these and other public health challenges. We conduct behavioral, demographic and health services research. We support national and state surveillance systems to monitor trends and identify gaps. We work with partners to translate research findings into public health policy, health

care practice and health promotion and disease prevention programs. Of note, our centers division of reproductive health insures routine surveillance of women's attitudes, experiences and behaviors before, during and after pregnancy, studies differences in health status, risks and outcomes related to race, ethnicity, age, geography and other demographic characteristics, and works with partners to address issues related to preconception care and safe motherhood. For over 20 years the Division of Reproductive Health has worked in partnership with AMCHP primarily through the maternal child health epidemiology program. A joint program of CDC, and HRSA. The goal is to build maternal and child health epidemiology capacity at state and local levels to effectively use epidemiologic research and information to inform public health action. Under cooperative agreement with AMCHP our division has supported multiple national and state projects including the state infant mortality collaborative. This is a five state project examining trends in infant and fetal mortality to determine factors associated with infant mortality rates. The women's health information, series of conference calls and webinars to inform states in localities on topics in women and infant health. The AMCHP innovation station focused on developing and sharing state best practices. And

a project on integrating chronic disease and MCH research beginning with an examination of gestational diabetes. The center's Division of Adolescent and School Health also funds AMCHP to provide capacity building assistance to MCH professionals.

Current activities include AMCHP participation in the National Stakeholders Collaborative working to strengthen collaboration between state health and education agencies around adolescent health issues including teen pregnancy. Hosting an adolescent sexual and reproductive disparities summit at this year's conference to share knowledge on adolescent sexual and reproductive health disparities, explore promising approaches and develop work groups to advance effective strategies. Hosting an adolescent reproductive health information series showcasing promising and evidence based practices in adolescent health and highlighting national initiatives and resources. And finally, supporting three states, Utah, Pennsylvania and Ohio to implement small scale adolescent and young adult preconception care projects. At the chronic disease center we're addressing difficult entrenched problems that often require complex multi-faceted interventions. It's only by working together and making progress on myriad parts that we will be successful in advancing the health of all Americans now and into the future. I certainly look forward to working with all of you. Thank you.

(Applause)

MICHAEL FRASER: Thank you Dr. Bauer. I just wanted to take a minute of our program to also ask Dr. Ed Trevathan the director of the National Center for Birth Defects and

Developmental Disabilities and our Past President Nan Streeter to come to the stage and while they're coming up would all of our colleagues who are currently working at MCHB, HRSA, CDC and any program please stand so we can recognize you for your partnership and your contribution to the states programs. (Applause) Thank you all.

Thank you for being with us. Well I'd like to ask you Dr. Trevathan and Bauer if you don't mind to just come to the front of the stage to receive a special recognition. As you both know, the H1N1 outbreak was a very significant public health emergency one that did test our federal state and local health departments capacities and I believe did a good job coordinating and responding and AMCHP would like to recognize the leadership that the CDC provided during the H1N1 outbreak by sharing a special recognition with both Dr. Bauer representing the chronic disease center and Dr. Trevathan representing the Birth Defects Center. I'm going to ask Nan to say a few more remarks as I get the awards.

NAN STREETER: Great, this award is being presented as Mike said to...we had a little bet going so Michael will explain it to you in a second. So where are your sunglasses? You need your sunglasses.

MICHAEL FRASER: Is it backwards? (Laughter) The things we do for love.

NAN STREETER: And the reason we're doing this is because we had a bet. AMCHP had a bet with Ed that if the rate of women who were immunized for H1N1 exceeded 70% is that correct? We would wear a pink wig...

MICHAEL FRASER: Ed would wear...

NAN STREETER: Yeah, well Ed doesn't want to wear. I was trying to reframe it. Anyway...I just want to say that this award is presented to the Centers for Disease Control and Prevention, the National Center for Birth Defects and Developmental Disabilities and the National Center for Chronic Disease Prevention and Health Promotion Division of Reproductive Health for their outstanding leadership and efforts to ensure that a critical focus was placed on maternal and child health populations during the H1N1 planning and response. (Applause)

MICHAEL FRASER: Okay hang on one sec. Next year Dr. Trevathan said he's going to wear the wig next year if you cross 70%. Thank you very much. (Applause) Obviously there were a lot of folks who worked on that response and we just want to quickly mention a few of the folks supporting the maternal and child health team at CDC, Katie McFarland, Georgina Peacock, Amy Cordero, Allison Johnson, Juliette McKendrick, Patricia Merso, Cindy Moore and Wanda Barfield all worked tirelessly to make sure that women, infants and children were considered during the H1N1 outbreak and we appreciate that. Let's give them a round of applause as well. (Applause) I think that boa looks great on you. That boa looks fantastic on Nan.

NAN STREETER: Well that's because I'm getting ready for the Oscar's.

MICHAEL FRASER: Absolutely, absolutely. We better hurry up, we better hurry up. Well as we transition to our next session I'm going to leave the stage and invite Nan to introduce the next section of our agenda, Nan?

NAN STREETER: Well now it's time to get to some seriousness, but good seriousness and that is we're going to transition from the welcome session to our tribute to Dr. John C. McQueen and the McQueen lecture award. This annual lectureship is awarded to honor one of AMCHP's most distinguished members, Dr. John C. McQueen. The former director of the Iowa Child Health Specialty Clinics, the state's program for... Dr. McQueen was a pediatric neurologist and he achieved success at state and national levels as an administrator and a clinician, advocate, and innovator and educator. Dr. McQueen made his presence felt throughout the country through his tireless work on behalf of children with special health care needs. AMCHP takes special pride in those accomplishments that have advanced family health programs. John passed away last year but his legacy lives on and on this 75th anniversary of Title V it is fitting to remember one of the block grants most vocal champions. Here to share some memories of John is another vocal champion for the block grant; AMCHP's good friend and MCH advocate Josie Gellar. Josie, I'd like to invite you to the podium. (Applause) Josie is a professor of law, pediatrics and nursing. Quite a combination there, got all the good stuff, at the University of Iowa and she worked closely with John and other MCH leaders during one of the most challenging times for Title V in the 1980's. Josie, thank you for being here with us this evening and I'll turn the podium over to you.

JOSIE GELLAR: I'm very pleased to be here to pay a brief tribute to actor John Charles Mc Queen. I find that being here is bringing back all sorts of memories of John to me. I really had the very deep privilege and honor of being his colleague and friend for nearly three decades up to his death last September. And he does I think leave a large and very enviable legacy of contributions to improvement of health care for pregnant women and mothers and children including children with chronic illnesses and disabilities and their families. I think John thought of himself first and foremost as a practicing pediatrician. He continued no matter what his other positions were to see patients, children and their families and he literally provided care over the course of his professional life for thousands of children. His professional life spanned the worlds of academic medicine, public health, private practice and public policy. For most of his professional life he was a member of the faculty at the University of Iowa College of Medicine and he was also Dean of the College of Medicine and served in various administrative positions at the College of Medicine. And of course it has already been alluded to for a number of years he was director of Iowa's Child Health Specialty Program. Iowa's program under Title V of the Maternal and Child Health Services block grant for children with special needs. He played a very important leadership role in AMCHP and serving among other things as its president. He likewise played an important leadership role in the American Academy of Pediatrics serving as President of the AAP and in addition he and I founded and co-directed the National and Maternal and Child Health Resource Center now called the National Health (Inaudible)... Policy Resource Center at the college of law as opposed to the College of Medicine and people had some trouble figuring that out but, suffice it to say that the list of his other

positions and activities is very long indeed. And I don't really think that they tell you about John's contributions.

My relationship when you look at the totality of his professional life was in the latter part of his professional life. It began in 1981 after that AMCHP meeting that Peter told you about he came to see me in April of 1981 at the College of Law where I was a faculty member and he said he needed to talk to me because of my knowledge and experience with respect to child advocacy. He told me he had been asked to put together an adhoc effort to save Title V and the situation was this...now this is ancient history I suppose but I think it's maybe still relevant today to today's...what's going on today. Ronald Reagan had been elected President of the United States and he had swept into office with him many Republican congressional candidates. As a consequence the administration was really exercising effective defacto control of congress. And the Reagan Administration was determined to cut spending for domestic programs. It was pushing for the repeal of Title V as well as a host of other health and human service programs and was proposing to replace them with block grants. If those...if the administrations proposal had been successful it would have meant that there would have been no specifically designated monies for the maternal and child health programs and the crippled children's programs established under Title V. AMCHP and the AAP had Washington lobbyists and John said they had told him that they didn't think that there was much that they could do to prevent the repeal of Title V. And with some trepidation I told him that I disagreed I thought that Title V might be saved provided that a grass roots advocacy movement was created that targeted key senators and

representatives. Well John decided he wanted to do that and as was John's want he got me involve in doing that. And over the next three months we created a grassroots advocacy effort in essence from scratch. We fought a lot of battles and we worked literally night and day. We would start at 7:00 in the morning and make calls to people on the East Coast and about 7:00 at night with calls to people on the West Coast and we organized some 17 trips to Washington for people to advocate for Title V with the targeted senators and representatives. I truly believe that this effort which was successful in preventing the repeal of Title V wouldn't have been successful without John. So I would say to John all right, we need to get to this senator in this state, this congressman and at that time they were all men, in this district and he would invariably think and then say well I know so and so and so and so I've worked with them. And then he would call them up and having done a lot of advocacy before I started working with John I was always amazed at how people never said no to John when he asked for their help. And it had I think something to do with the respect and esteem in which he was held. He also was able to get the leadership of some 13 different organizations which had different interests and didn't always get along together and that's putting it mildly to work together on behalf of Title V and so Title V was not repealed it was amended and as Peter said it became the Title V maternal and health services block grant. I do have to say that although it was amended and amended significantly it preserved its essential character and resembled more of a traditional grant and aid formula program than a conventional block grant program.

Now this story had another chapter. At the end of July John and I...heaved a great sigh of relief we can go back to doing what we were doing before the crisis. But then the Reagan administration embarked on an attempt to eviscerate the Title V maternal and child health services block grant programs by flashing their appropriations drastically. So we were called back into the battle again and asked to continue our advocacy efforts and we agreed to do so and we created the national maternal and child health resource center in order to do so. It took us several years and really many many hard fought battles but we were finally able to increase the appropriations to a sustainable level. so I do think at least in my view the fact that we can now celebrate the 75th anniversary of Title V, John deserves a great deal of credit for that. (Applause) I've given some thought to what of John's many accomplishments he would most like to be remembered for and I'm not sure but I think it would be this: in his capacity as Directors of Iowa Child Health Specialty Clinics he developed a statewide multi-agency system of centers that provided community-based family centered and coordinated care for children with special health care needs and their families. That then became one of the primary models for a national initiative of the Maternal and Child Health Bureau and the U.S. Surgeon General's office and he played a very key part in the development of that initiative that served to promote family centered community-based coordinated care. I think that if John were here today he would say he would like his vision, he would like to be remembered for his vision, statewide systems of community-based family centered, coordinated care. It's a vision that has not been fully realized but I think due to his work at least we have some hope that ultimately it will be fully realized. And I think above all that he would like to be remembered and I say this sincerely as a good pediatrician who

did his best to help the many children for whom he cared. When he died I got some very touching notes and emails from parents of children and actually from two children whose pediatrician he had been and they were really touching. One of the notes said he was a doctor with ears by which I think was meant he was a listener and he was also a doer from what you can probably tell from what you've been hearing about him. I'm glad that John has been and continues to be recognized at the AMCHP annual meeting through the McQueen award and presentation. I felt a very great loss when he died and I just want to end by saying he was a truly great man and he was a truly wonderful human being, thank you. (Applause)

NAN STREETER: Josie, thank you so much for many of us who never had the pleasure of meeting Dr. McQueen of telling us about his accomplishments and what a grand person he was. It's my pleasure now to invite Kay Johnson. Many of you know Kay. Kay is a wonderful MCH advocate and policy person and so we would like to ask you Kay, to introduce our 2010 McQueen (Inaudible)...

KAY JOHNSON: I'd be happy to. This is truly an honor for me. I'm going to make sure that I've got a slide here. I'm not going to give a speech but I am going to show a few slides and tell you by way of the slides and my words a little bit about Sarah Rosenbaum. As a scholar and educator, a national health policy leader, Professor Rosenbaum has dedicated her career to promoting more equitable and effective health care policies in the United States. Her work has focused particularly in the areas of Medicaid and Medicare, managed care, health employee benefits, Maternal and Child

Health, community health centers, and civil rights across the U.S. health systems. Her commitment to strengthening access to care for low income minority and medically underserved populations has had a transforming affect on the lives of many Americans and particularly on its children. So when I first met Sarah, when I was hired by Sarah in 1983 so if you're following the history here, you know we've got Peter telling part of the story and Josie telling part of the story, now I'm picking up after the block grant has been enacted and the states have just you know...made the dust settle and keep going on as Peter described to you. Sarah had become the director of the health division at the children's defense fund following a career in legal services. She'd traveled the frozen back roads of Vermont, she'd brought important cases to protect the rights of impoverished Medicaid and Medicare beneficiaries and her commitment to and knowledge of the lives of poor children and families was already very strong. So the work of that time and the work at CDF, the Children's Defense Fund may not be familiar to the younger members of this audience. Times were not good for children and pregnant women in the early '80's. The creation of the block grant under the Reagan Administration had drastically cut the funding to states. Medicaid coverage for children because it was tied to welfare and nobody wanted to make welfare payments it had dropped from 84% to 74% of poor kids even while the number of poor children was increasing due to a recession and infant mortality rates had plateaued insuring women who were uninsured who were giving birth in parking lots after being turned away from emergency rooms and it was my job the first summer I worked for Sarah to call every Title V and children with special health care needs agency and find out about the things that I just told you. So Sarah's strategic and analytic brilliance was that she assembles

good people, she has incredible ideas, she seizes opportunities as a true policy entrepreneur does. She assembled then a small team to use data and advocacy to drive change.

It started with a focus on reducing infant mortality and improving prenatal care. It led to incremental policy changes between 1984 and 1989 and 1990 excuse me that extended Medicaid coverage to millions of children and pregnant women. And the policy changes of that era also included improvements to Title V in 1989 in order to strengthen the program following creation of the block grant. Sarah, Dana Hughes and I as well as others who worked with us over the years developed what became known as the data book and it tracked maternal and child health statistics and policy changes over a decade and that work really laid the groundwork for things like the kids count system, for some of the indicators that are actually in the TVIS system to day and other maternal and child health data indicator projects. Its not that people hadn't thought of this before but we were systematically hammering this out for ten years. Sarah was involved in the creation of the modern AMCHP helping the association leaders create a Washington office in D.C., helping to hire its first director, Cathy Hess, and identifying individuals who could lead the lobbying efforts there. Sarah's contributions are however much larger than the MCH policy pieces I've described. Between 1993 and 1994 she worked as a member of the White House domestic policy council under President Clinton and she directed the drafting of the Health Security Act, also known as the Clinton Health Reform plan to you and oversaw the development of the vaccines for children program. And as George Washington University created a School of Public Health, she

was...became the founder and chair of the Department of Health Policy and the Harold and Jane Hirsch Professor of Health Law and Policy. In the early 1990's when managed care emerged as a common practice Sarah recognized that managed care contracts were a critical new component of the legal framework for health care. She assembled a team of 8 to 10 lawyers, I was trying to remember actually the count and analysts together and to put those contracts, it combined them and sliced them and diced them in a way that could make sense to regular people not just lawyers. It resulted in a 2000 page report, a searchable database and the Health Affairs article that you see there today. With the work of a team at GW that included me and Colleen Sinowski, and Ann Marcus whose leadership continues there today Sarah led critical analysis of the passage of S-chip and published the first article about the new program and its effects and what they might be. So through her devotion to issues affecting low income minority and medically underserved populations Sarah has been a great inspiration to many others. As a mentor and she is a mentor and a friend of mine, she is drawn she says to young people interested in improving health care for the poor. She says I'm always on the look out for students who have a keen desire not only to learn health policy but to apply their knowledge to systemic problems that disproportionately affect low income medically underserved and disabled children and adults. She is truly also a beloved colleague to many people in Washington and has been so over the years. She's the author of more than 250 articles and studies focused on all phases of health law and health care for medically underserved populations. She's co-author of Law and the American Health Care System, a widely used health law textbook. She's been named one of the nation's 500 most influential policymakers by McGraw Hill and her opinions

are sought by experts at the New England Journal of Medicine at the Journal of the American Medical Association as well as health policy advocates and academic institutions here and abroad. Among her many other honors, Sarah has been recognized by the Department of Health and Human Services for distinguished national service on behalf of Medicaid beneficiaries. She trained at Wesleyan University and got her law degree from Boston University School of Law. She is a loving mother; friend, daughter, sister, and wife and you're going to get to hear some of her brilliance in her talk, thanks. (Applause)

NAN STREETER: Thank you, Kay, that was great. And so now I'd like to invite Sarah to join me up here at the podium...so I want to acknowledge on behalf of AMCHP all your contributions. I heard you talk a long time ago, not that long ago, and have been a great admirer of yours...

SARAH ROSENBAUM:...40 years.

NAN STREETER: No, it wasn't 40 years ago, so I just want to thank you so much for your leadership and your partnership and your innovative thinking relative to MCH and policy.

SARAH ROSENBAUM: Well thank you so much, I am so honored, thank you. (Applause) Thank you everybody. I know that I stand between you and the capitol steps. They are the ones who walked by and...they're absolutely wonderful so I will be

relatively brief. It is a great honor to have been selected as this year's John McQueen award recipient. I was very fortunate to know Dr. McQueen, admired his work greatly. The award carries enormous meaning because of what Dr. McQueen did, what he contributed, how many other deserving recipients of this award there have been and the recognition of peers that it signifies and as Kay knows it was incredibly painful to sit through that introduction, it was just beautiful. You know it's funny to watch things. Kay did not tell you what it took us to put those reports and studies together those of you who go back pre-computer...(Laughter) I cannot tell you. We literally spent days and days in CDF's offices with tape and scissors and Xerox machines and I...in the middle of the whole thing, Kay who was technologically well ahead of her time announced that I had to learn to use the computer.

It was the mid 1980's I didn't know how to Word process. She said it will change your life. And I can remember one Saturday afternoon; it was like learning how to ride a bike. I sat and wept at a computer for about four hours until I learned how to word process and after that the rest was history. People who know me best, the incomparable Kay Johnson who has been my friend and my comrade over so many years now really decades, I was very fortunate to find her and hire her when she was a graduate student who had this little spiky hair, was a student of Arden Miller's at Chapel Hill and my incomparable husband, Dan Hawkins who is absolutely one of the guiding lights of my life...those of you who know me best know that despite everything that I have done over the years children have really been the touchstone of my time as an advocate and a lot of what I do today even when it seems to involve issues that have nothing to do

particularly on the surface with children I manage to sort of bring back to children in my own head if not vocally because they are...there's nothing like children really, they're very compelling. They are very compelling as humans and they are very compelling for the intellectual aspects of their...of what they bring to public policy. I think that has been a part of, in fact in some ways the most gripping part of it for me is what it is about children that makes such a powerful case for social investment. And my career has been one about making cases for social investment. I think a lot of us would probably be very happy if children could somehow live above the political fray and the fray of the give and take of policy. You sort of think of children as such incredible assets to society that without a whole lot of prompting by public policy makers people would invest in them, they would give them the best of everything. They would give them the best food, and the best schools and the best home existences in terms of parents who were well educated and strong and they had good incomes and had the time that families need for their children. Good quality childcare, all of these things that you just assume that children would have and when and if they were sick or had a disability that they would get absolutely the best of everything. The most rapid, the most enduring, the most accessible, the best quality health care and it would be health care that would go on uninterrupted as long as they needed it. Not only because children are such an asset but because really what they need does not even begin to make a dent in social welfare spending if you look at what children cost, what they cost the state Medicaid program in your state, what they cost in the way of benefits paid under other programs, what their education costs, there are certainly costs but compared to the GDP of this country it's not even a bump on a log. And yet despite all of this children are a really...in terrible

shape and it seems so contradictory to how valuable they are to us and how little it takes actually to make strong children. How little material investment it takes.

Right now we live in a time when one in four children and one in five...excuse me three in five minority children lives in families that are euphemistically termed low income households. Low income household being of course twice the federal poverty level. I don't know what it's like in the state that you come from. Where I live in Northern Virginia twice the federal poverty level would not even begin to pay half of a month's rent on a modest apartment, much less being able to really raise your child with all of the things, not huge material things but all of the things that children need whether it's signing up for a spring soccer program or taking swimming lessons or going to the movies or just having a little bit of money to be silly. I mean those are the things that children need so you can do nothing at twice the federal poverty level. And the moral imperative for reversing this situation is just so grave that for those of us who've been advocates for children all of our lives I think the moral driver behind child advocacy is what's always struck me, both the moral driver and then this question about how could it be that a society as wealthy as the United States simply has failed to invest in it's children in a meaningful way. I think the most disturbing figure that I came across...when I was in Children's Defense Fund of course I spent my life...anybody who knows the astounding Marion Edelman knows that you spend your life if you work with her looking for statistics so it was a while since I had looked at a lot of children's statistics and the one that just really killed me was the figures on children today who were living in extreme poverty at below half the poverty level. It's the worst numbers that

we've seen in 15 years. If ever there were a testament to the importance of social investments and the problems of living in a time of really great, the greatest social Darwinism I think that we've seen, certainly I've seen over my professional career. You can see it in the rise of children living in extreme poverty. Ironically though in some ways the terrible poverty of children has made it possible to have dialogues around government investments that otherwise don't happen in this country because we tend to associate government investment with need which means that we often have programs that are not universal in nature they are targeted programs and as the problems of children have become more and more evident the case for government intervention of course has become greater. We can think about lots of different programs that have followed this arch. Health care has been a particularly important one because of how far we've come.

When I began my work in the late 1970's at the Children's Defense Fund we were...I joined CDF in 1978 and we were in the throws of at that point what became the losing battle to get the first Medicaid expansion for children enacted. The Carter Health Reform Plan had long since collapsed, what was left were a few pieces that were still moving, one of which was for those of you who remember this remember CHAP which as I recall Secretary Califon always used to call it CHAPs and I always have this vision of a horse riding into the sunset but we were trying very hard to get CHAP passed and the big ask and it turned out to be far too big an ask was not just to make it possible for all poor children to get Medicaid not just the ones who had welfare as well but to set a national income floor of 50% of the federal poverty level and we could not convince a

critical mass in the senate to back an amendment at 50% of the federal poverty level so we took the change we could get which was the decategorization of coverage. But the senate at the time was content to leave Medicaid at well those of you from the states with the most limited benefits know we had children at that point who could not get Medicaid if their incomes were above about 20% of the federal poverty level. So we could not get a national income floor out of the senate. The House did pass one and of course the bill died. It died in the last months of the Carter administration a victim of many things, a Republican victory, another great period of social Darwinism and the battle of course brings back a lot of recollections for what's going on now, a tremendous battle over abortion. Again those of you who go back to the mid-70's may remember just how bad those battles were.

That was the beginning of the anti-abortion amendments and when CHAP was considered in the House of Representatives one of the very first of the so-called Hyde amendments was attached and so it was so burdened down that we could not even get children up to 50% of the federal poverty level in terms of their Medicaid coverage. Now it took only a couple of years, it took a few years and a remarkable thing happened and it was I think a result of this reaction to the kind of lashing out against public investments for poor children that you've now heard about that of course Josie so eloquently described with respect to John McQueen's work that Peter Van Dyke read when he read the old pamphlet. And an astounding thing happened following the mid '82 midterms, which was this turnaround and so one of the great champions in fact of the Medicaid expansions for pregnant women and children ultimately became Henry Hyde.

It was Henry Hyde who shepherded the first expansions with Henry Waxman through congress.

The period that Kay mentions from the early 1980's up through 1990 were sort of this period of positioning a lot of programs for expansion and improvement and building and it was a very heady time. It was very incremental, it was very unlike today but in terms of the sheer breadth of it and it was all done on reconciliation bills pretty much I might add. (Applause) But tremendous gains, tremendous in Medicaid program it wasn't just children there were huge gains for the elderly as well and for people with disabilities. The program was fundamentally restructured. Just...it was done in a way that nobody quite noticed...somebody once gave a name to it...of course the great architect of all of this was Henry Waxman and his programs were known as delayed action fuses because he would sort of sneak up on you with these small changes that cumulatively amounted to a major restructuring of the program. We stand at sort of a remarkable moment today when we are poised potentially as you've now heard in case you had missed it somehow to hopefully pass final legislation enacting health reform in the next several weeks. It is a...it has been the struggle of the century. It has been a year here like no other I think any of us has ever lived through. The legislation is obviously not perfect but it is an astounding, it is transformational and its' importance for the American health care system. Some of the effects will be seen in the coming few years, some will take much longer because contrary I think to a lot of the press coverage there are actually major changes built into the legislation to sort of reorganize and restructure health care. It takes a long time to change the health care system and as a result you

really cannot expect legislation to pass this year and next year have a transformed system. In many respects the legislation really is the easy part though. A lot of the legislation involves what the government does best. What the government does best is move money around. I mean if you think of the government like a big public banking system in some ways it takes money in and it moves it out. And the easy thing in health reform and I say this as an insurance lawyer in awe of people who are health care provider and health systems people, the easy thing quite frankly is to move the money around so that everybody has stable and continuous insurance. That's actually...there are several different ways to do it we've...as the President pointed out last week talked about all of them, we've settled on a couple of them, the time for talk is over, it's time to move the money, it's time to get this piece done so we are no longer an embarrassment among civilized countries. (Applause) And at that point...at that point it's possible to get down to the hard work. We have never had a period when children and their families could be stably attached to the health system. Children's coverage comes and goes even with all the expansions we've been able to make happen over many, many years. It has been just a terrible odyssey for families who can't stay attached to health insurance coverage and what health reform promises to do for us is for most children and there are some who will be left out but for most children get them attached to a health system, both to clinical care and to an array of programs that hopefully in the coming years will be aligned better with clinical care programs and to all of the other services and supports the children need. But first comes the insurance, after that comes the hard part and I think this is where Title V has an enormous role to play and I'm hoping and assuming that a lot of your discussion comes in relation to how do we

change ourselves, what do we need to do in a transformed system? So I thought that I would touch upon just a few of them, the ones that strike me as the most important. The first one is children who are undocumented or who live in families with parents who are undocumented. They will not get the benefit of this. The ones who are undocumented will not get the benefit of these reforms because they will be excluded. But the far greater number of children who live in families where a parent or a caretaker relative is undocumented our children who are...will be totally eligible for the coverage but their families will be very fearful. Their families will be extremely fearful about seeking out the coverage. MCH has to find these families and help them. There are millions of children in this situation. This is not a small number. A very small number of children are undocumented but a considerable number of children at least according to expert estimates are caught in this world of fear over coverage. This is something that local health, public health, working with community health centers, Head Start programs, other services in the community school systems, a place to make an enormous contribution which is how to find and connect every child who is entitled to it to coverage and how to help families understand that they don't have to be afraid of their children's health insurance coverage. Benefit design we will have uniform coverage standards undoubtedly if health reform is enacted and those standards will be pretty good. They will be the coverage standards that probably characterize coverage for most of us in this room. But we know from the work of Dr. McQueen and we know from other leaders in this field like Julie Beckett and from many of you who have worked on this issue that benefit design and the adequacy of coverage is just crucial. To that end of course the greatest, the greatest achievement ever in this country in terms of a fully articulated

vision of child health was the Medicaid EPSDT benefit which is still when you read the original language from the 1967 legislation your breath is taken away because you understand that somebody understood what it meant to provide early treatment so the word early in the statute does not just define screening it defines the treatment and of course EPSDT was added after Medicaid was enacted so people understood that the benefits that were given to adults were not adequate for children and the really majesty of the EPSDT has been continuously foiled over many years. Many of us have made sort of runs at strengthening improving it. It works in miraculous ways in so many states and somehow we have to translate what it means to cover children in Medicaid to all children. And that's going to be a great piece of unfinished business in this bill. A third challenge will be the affordability of care. The coverage will be there, it will be adequate coverage but lower and moderate income families will be left with a pretty significant, still, financial burden of illness. Particularly again for families whose children have serious illness and disability. They will have protections that they've never had before but those protections will not be enough. We're going to have to come back again and again for that. Quality and access issues that go hand in hand this is where I think the MCH program has shown over so many decades now being able to be out front on the actual delivery of care in communities where are resources needed? Where are investments needed? Preventive investments, more significant health care investments for children whose needs are greater, for families whose needs are greater, now in an electronic age, ushered in of course by Peter Van Dyke well ahead of the rest of us but truly as we become much more adept at electronic information and users of health information technology the importance of modernizing, making sure that every MCH

program is able to command the kinds of attention on surveillance, on registries, being able to match for example community asthma in real time at the community level among children against the proportion of children with diagnosed asthma who are in treatment. I was stuck I just finished a report on childhood asthma something that I knew very little about going into it and was astounded actually how little we understand asthma's impact on children at the local community level because there is very little real time data on the presence of the condition. Finding the data, monitoring health status, monitoring chronic conditions, monitoring preventative health services, and then using the data to advocate for a strengthening of child health services I think remains the hallmark of Title V and everybody's going to need you now more than ever in an age of health reform. And finally of course there are other social determinants of health which really won't be touched by health reform. A little bit there will be very important money to develop service capacity, to invest in community prevention but the social determinants of health I'm afraid lie beyond the furthest bounds of the health care system in fact a lot of the problems of course of the health care system is that it's very much burdened by the lapses in this country around social determinants of health. And here is where I think going back to the roots of Title V and Shepherd Tanner it's going to be extremely important for Title V agencies to see beyond the limits of the systems over which they have immediate responsibility or jurisdiction into the broader issues of conditions affecting children. When we have the highest proportion of children living in extreme poverty in 15 years it's simply very difficult to make progress. This is of course the 75th year of Title V of the social security act. It seems only fitting that we should move

forward with health reform and hopefully another 75 years at a minimum at Title V.

Thank you. (Applause)

NAN STREETER: Isn't she great? Thank you so much, Sarah. As I mentioned before I had the pleasure of hearing Sarah a number of years ago and I've been very impressed with her ability to analyze health care coverage and all the issues associated with changes in coverage for our nation's kids and moms. I have the great pleasure of introducing our final presentation and I know you're tired, you've been sitting but I'll tell you if you have never seen Capitol Steps you're in for a real treat. And so you think about David Letterman and Jay Leno and others who have made great jokes about the D's and the R's and everything in between. Capitol Steps is a wonderful group that I know you will thoroughly enjoy, so enjoy.