

2011 AMCHP and Family Voices National Conference: Partnerships Are Key in Measuring and Improving Quality in Child Health

02/14/2011 Omni Shoreham, Washington, D.C.

NORA WELLS: Partnerships are key in measuring and improving quality in child health.

We have four distinguished speakers here today and I'm going to let each of them introduce themselves and we hope each will spend about 15 minutes and we'll have some time for question and answers.

And we will start with Pat.

PAT HYNRICK: Good morning. So my name is Pat Hynrick and by way of introduction

I will share with you that I was born at 28 weeks in 1952 and there was no partnership with families then. My mother was not allowed in what was loosely – would now be called a NICU but there were no NICUs back then. There also was no resuscitation; I was baptized four times, that's all they did to me.

I spent a month in the hospital until I have five pounds; that was the law in Massachusetts. My mother was not allowed in the nursery for the month and then they called her and told her to take me home. So my mom's a nurse; I always wanted to be a nurse. I'm a nurse by background. I'm a neonatal nurse, a perinatal nurse, and after many, many years nursing and many capacity, different capacities, I switched to quality improvement and I've worked for 13 years with the National Initiative for Children's Healthcare Quality and then started a consulting business of my own last year. I do still work for NICHQ. And the program that the program that I and Terra are going to be talking about was a NICHQ program funded by CMS. So thank you for the opportunity to be here.

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We're going to talk about quality and then we're going to talk about partnerships. So I mentioned NICHQ, let me tell you just a little bit more about NICHQ. It's a non-profit organization founded in 1999 as a program of the Institute for Healthcare Improvement and then became a separate non-profit after that. The mission of NICHQ is to improve children's health by improving the systems responsible for the delivery of children's health care. That's done in many ways, but the program, as I mentioned that we're going to talk about today, was called the Neonatal Outcomes Improvement Project. That program was funded by CMS through transformation grants and those were awarded to first Ohio and then North Carolina. Terra's going to be telling you about that program. Also Arkansas. And the New York State Department of Health funded New York to join that, too, and both the work and all four of these states is ongoing.

Let's start about what is quality. I love this quote. "I don't know but I know it when I see it," and I think probably many of you feel that way as well. The Institute of Medicine defined quality in 2001 as the degree to which health services for individual and populations increase the likelihood of desired health outcomes and are consistent with the current professional knowledge. So that's what quality improvement is and NICHQ that's what I've devoted the last half of my career to translating evidenced-based medicine, to doing what we know works, doing it sooner than the 20 years it often takes after new guidelines and recommendations come out, and translating that evidence into practice.

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Quality's been called a lot of things over the years; you may recognize these initials. It's pretty funny. It's all the same thing. We're really trying to get optimal outcomes. So the things that really are similar to all the programs over the years are the organizational commitment to quality and really the focus on the customer. So you'll hear much more about that with our partnerships talk.

Fixing systems. You know you can't just do work harder one doc at a time or one person at a time. You have to change the system or it doesn't sustain. Teamwork is essential. I've been promoting the idea that we need multi-organizational teams with families on them since I started this work. There's no quick fix and I will tell you that every project I've worked on for 14 years people always realize at the end of the project it's never the end of the project. So I'm sure you've experienced that as well.

Quality has evolved over the years and I'm going to go through some of these slides fairly quickly because our time is so limited but you can access them and download them and read every little detail if you like, but I love to go back to the beginning of quality with Florence Nightingale and I'm sure you've all heard of her quality improvement in the military. Over to the more recent, which is the Institute for Healthcare Improvement and NICHQ and MCHIP and Family Voices and all of the different kinds of projects that you work on.

The father of quality is often considered to be Edward Deming and he worked with Toyota in the business – the realm of business.

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Then he came to healthcare and really has taught us many things that we – theories that we work from to this day.

The part I'm going to be talking about is the model for improvement. The model for improvement is really a method to help you increase the odds that the changes you're making are improvements. Now we know that all change is not an improvement. Anybody have a thought about something that changed that really wasn't an improvement? No?

How about anybody have a teenager?

Audience: Yeah.

PAT HYNRICK: Now you think about changes that are not improvements. My favorite is those pants they wore somewhere around their pubic bone that drag for about three feet behind them and then they didn't care if wash them. Anyway. You obviously – I used to have teenagers. But all improvement does require change and change is challenging. So all improvement is challenging.

This model was developed by the Associates in Process Improvement and it was originally used in healthcare with the Institute for Healthcare Quality and it has three questions. What are we trying to accomplish? How will we know the change is an improvement? And what changes are those? What do we want to change and see better?

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You may have heard of the PDSA cycle, the Plan Do Study Act or the Plan Do Check Act, and that's really what I'm going to talk about today. So you can think about, when you leave here, what do you want to change? How will you know if it works and what kind of results will you get?

We start with the AIM, the AIM statement. I like to say if you're going for a drive and you're just going for a drive, you'll end up somewhere but maybe no destination and planned. If you're planning to drive out on a Sunday and end up at a restaurant, you better know that's where you want to go or you might not end up there. An AIM statement is the same thing; it's a clearly defined statement of what you're trying to accomplish with your project or your effort and it helps answer the question. It helps create a shared language that can be used across your organization, so it really facilitates that communication and it also supports accountability for the team and the leadership as well.

We like to say smart AIMS. The components of smart AIMS are specific measurable, actionable, and achievable, relevant, and timely. Now you might have noticed from my accent, I'm from Boston, so we call that a smart AIM. So we had to separate the action and achievable.

The second question of the model for improvement is measurements and sample data. The question is how will we know a change is an improvement. And you need to measure that. You need to study it to be able to tell if it's an improvement. Anybody like sort of not really love data so much?

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When I started quality improvement I said to Charlie Homer, the CEO and President of NICHQ, “You do the data and I’ll do all the other stuff.” And he was like, “It doesn’t work that way.” So data is important. But since then, I’ve also worked with people that thought if they make regulations and demand that people make improvement and they’re going to measure them, they’ll improve and sometimes that works and often times it doesn’t. Because it’s not a cow and even if it was you couldn’t fatten it just by weighing it.

So you may have seen this Three Faces of Performance Measurement Improvement Accountability and Research grid. This was by Solberg, Leif Solberg and some other really smart people that knew much more about this than I do, but the reason I show you this slide is there’s really a big difference between data for quality improvement and data for research. Often times when people are working on quality, they are researchers and they’ve participated in research projects and so they’re thinking research. Quality improvement data is really just to study if you’re making the improvements. So we ask you to display data over time so that you can really see the data is an improvement. If you look here, the change in the top grid doesn’t have any effect on the graph. We’re trying to go lower; this **** cycle time.

All three graphs start at 70 and end at 35. So if all you measured was beginning and end, like taking a survey at the beginning and end, and looking for some difference based on your changes, you wouldn’t know. You’d know it was an improvement but you

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wouldn't know which change resulted in the improvement. So that's why we look at changes as related to what the beginning, the end and every interval in between. We like to encourage people to really measure more frequently so you can really compare the changes.

The bottom two slides, they made changes that did result in improvement. But you notice anything about this third slide? It wasn't sustainable. The system wasn't changed. So as soon as they started a different project it started to go back up. So you have to continue to monitor what you worked on to be sure it's sustainable. You may not collect data every month at the end of the project but maybe quarterly.

So the third question for the model for improvement, the final question, is really what changes can you make that result in improvement. You may have theories or hunches, you may have a prediction that something's going to work, but as I mentioned you don't if it's improvement unless you measure it and you study it.

So the PDSA helps you translate that prediction into something that you can do and then study. Plan it well, think about how, where, when, why; all the pieces you need to do it, then do it, and then really study it and see if it accomplished what you wanted to. We like to say after this study you have three options. You can abandon it if it turned out really terribly. We're recommending you only test things with these PDSA cycles on very small amounts, either a small population or one doctor at a time, small so you can just sort of bury it in the carpet if it was really a dismal

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failure and no one will fire you. If it worked pretty well but you've learned something you can adapt it and measurement in quality improvement is really all about learning.

There is no failure; this is not pass, fail, not ABCDEF. This is learning. So if you've collected some data and you've learned something you adapt and you run your next PDSA cycle based on that and you make a prediction for that. Okay. The first time didn't work, so I'm going to do this. The next time maybe that will work. And you just run sequential PDSAs over time to get from a hunch and a theory and a prediction to the top, a change that really results in improvement.

Using PDSA cycles to really test better ideas. You plan them multiple periods ahead. You scale down; remember I said small. Keep it small. You can expand and do larger as you go up the ramp. This will minimize the burden of your work and minimize the burden of the data collection. You don't have to get buy in or consensus. Just take your friend; ask them to test something. Just take one willing volunteer, ask them to test something. This gives you a chance to be really innovative and you don't have to worry about disrupting your whole system. Your system's still running; you're just testing things.

And then in latter cycles, test over a wider variety. I like to say everyone starts everything on the day shift but the night shift is really different. If you're in a hospital NICU you'll know what I'm talking about.

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And finally, tips for success in quality improvement. Improvement occurs in small, small steps. You can't plan months in advance for a big giant change and then change it across the board with most things that you improve. Yes, you have to do that with your EMR and things like that, but quality improvement really occurs better in small steps with repeated attempts to implement new ideas.

Failing. There's no failing. It's just a learning opportunity. Remember communication and leadership are two of the key components of quality improvement projects that are successful. I'll leave you with a thought by Don Berwick before he left the Institute for Improvement and Maureen Bisognano, and they used to say continuously, "Remember, hope is not a plan. You need an AIM statement. Soon is not a time. Be sure it's time specific. And some is not a number." If you'd like more information about NICHQ you have that in your slide: www.NICHQ.org.

With that, I'll turn ***** -- I brought them from my room.

TARA BRISTOL: Thank you, Pat. I'm Terra Bristol. I'm the March of Dimes NICHQ Family Support Specialist at North Carolina Children's Hospital. And I serve as a faculty member for the Institute for Patient and Family Centered Care and work as an advisor for Patient and Family Involvement for the Perinatal Quality Collaborative of North Carolina and with Pat as parent faculty member on the Neonatal Outcomes Improvement Project with NICHQ.

So Pat gave an introduction, a very brief introduction, to quality improvement and now I want to just highlight an example of a

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partnership with families for quality improvement. So first I'd like to introduce you to my dear friend John Paul and his daughter Gabby. After five years of miscarriages and a stillbirth, Gabby was born on New Year's Day, 2009 at 25 weeks. And for a 25-weeker, Gabby did remarkably well. This is one of John Paul's favorite photos of himself and Gabby sharing a special moment. It's actually the first time he ever held his baby daughter.

After six weeks in our NICU Gabby died on Valentine's Day 2009, two years ago today, of a preventable infection. So after a few weeks after Gabby died our Medical Director met with John Paul and his wife and said, "Gabby's death could have been prevented." After the families questions were answered John Paul wanted to know just one more thing: what could he do to prevent this from happening to another baby, another family.

So that summer as the statewide quality collaborative picnic and our unit started our work on the CABS project preventing Catheter Associated Bloodstream Infections. We thought of John Paul and Gabby and invited them to be partners in our work and on our team and John Paul was invited to speak at the second day opening of our first learning session for the statewide collaborative and there was not a dry eye in the room as John Paul spoke from his perspective, as a parent, why it was imperative to work towards zero infections in our newborn intensive care units.

His message was so incredibly powerful that he began to invitations to speak across the state. This is him speaking to a nursing staff meeting at Duke University for their ICN group.

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What we wanted to make his message available to anybody who would listen and so I'd actually like to share a clip with you. So we're going to do a little switch out because of some technical issues here.

[BACKGROUND TALK]

Female: Bill Gates has technical problems too. Stand by.

[BACKGROUND TALK]

Female: We'll have to come back to that; we're having a little technical difficulties but ****. Trust me it was very compelling.

TARA BRISTOL: So in the video it's in total length about 11 minutes and shares his family's experience of hopes and dreams and how every family that you work with every day comes in to your clinic, your hospital with hopes and dreams for their child and he shares the day that Gabby died and he and his wife had left the bedside and he came back up and heard the nurse who was doing imprints, hand prints of Gabby and getting the clip of her hair and he heard the nurse saying, "I shouldn't be doing this to you. I shouldn't be doing this to you." And how true that statement was. This video is available to anyone who would like to have access to it to share with folks at home to talk about the importance of hand hygiene or to highlight how to engage patients and families. If you go to www.PQCNC.org there's a search box and put in Gabby and it will bring you to the video and you can download it and share it.

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One of the teams that really embraced the engagement of families was Duke's Intensive Care Nursery and they actually created a whole campaign surrounding the prevention of infection and they called it RAIN, Rally Against Infection. One of the things they created as part of this campaign was a letter for families and they did it in partnership with the families on their family advisory board. In the letter they highlight the role of the families and preventing infection and you can read here an excerpt, "Ask the doctor or nurse did you remember to wash your hands."

One of the other tools they use, they did education hours of different sorts but this is a screensaver they had in their unit and originally they were developed for the staff as reminders but what they found was that the parents, many who sit hour after hour after hour at the baby's bedside started noticing these and they were asking questions. This one you can see it says, "100 days since last bloodstream infection." And the parents wanted to know, well what is the BSI and what did that mean. Those were conversation starters with families.

This photo is of a mother – this was at our final learning session for the CABS I project – this mother's twins were in the Neonatal Unit at Duke during the course of the project and she spoke about the impact of receiving that letter and the messages she received about being a partner in preventing infection. And talked about how it was so empowering that actually when a surgeon came up to her baby's bedside and she hadn't seen him use any foam or

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scrub up that she felt able and supported in asking if he had done so.

The final learning session for our CABS I project was meaningful for many reasons. Not only had we accomplished this great amount of work with NICUs across our state, but we had partnered with families in unique and powerful ways. This is actually a photo of staff from our Newborn Critical Care Center. The very one was baby Gabby died. And here you can see John Paul standing with the team holding up a sign that says, “199 days since last bloodstream infection.”

It was important to me and our entire collaborative team that it not just be we’re paying attention to this now, we’re collecting data on it, but now we’ll move on to something else and it will go away. And it was especially important because we had engaged patients and families to give that commitment to them. So here you can see a poster we created that a number of the folks who attended the last learning sessions signed and it says, “We remain committed to continuing the work begun in the picnic CABS I initiative so that one day no baby is ever harmed by a preventable line infection.”

I hope that today as you go through your sessions and the rest of your time here you’ll think about ways that you can uniquely partner with families and how today two years after baby Gabby died what could have been purely just a tragedy, how it’s come to be such a powerful message to be shared nationally to partner with families and prevent infection.

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Female: You have five minutes.

TARA BRISTOL: All right. I guess we're going to try the video again.

Female: We're going to try one more thing.

[OFF CAMERA CONVERSATION]

[AUDIO VIDEO]

She was clammy and she didn't have any real color to her anymore. On paper looked great. Her stats were normal and she still didn't look right. She was clammy and she didn't have any real color to her anymore and she wasn't moving around and fighting when you would change her diaper, because normally she would kick and move and make little grunting noises and all that kind of stuff.

And that's when the antibiotics were started again and we found out that she had MRSA; we didn't know what strand of MRSA yet but she had MRSA and we knew that wasn't good. I'm still amazed at how fast it all happened. It was honestly just a matter of days from when we first found out until I was holding her head in the palm of my hand and feeling her heartbeat slowly fade away. And have my wife saying over and over again, "No, no."

I looked up and I realized that it was Valentine's Day. And in her fading heartbeat faded again the dreams of being a family.

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This is why I'm here now. I want to do what I can to help stop infectious diseases because Gabby didn't have to die. It's amazing or it's even hard to believe that something as simple as just simply washing your hands, that that simple action, that 10 seconds can last a lifetime.

I quietly walked in on the nurse that was cleaning up Gabby after everything had happened, and after she died. She was clipping some of her hair. She had just put her dress on her and she was cleaning up and when I walked in she was actually doing the foot imprint. She didn't know I was standing there watching her. And she was bent over Gabby and slowly and quietly whispering to her, "I shouldn't be doing this to you. I shouldn't be doing this to you." And she's right. None of you should ever have to say those words to a child because of an infectious disease caught in the hospital.

So let's stop infectious disease. And let's do what we can to help keep a family's dream alive.

[OFF CAMERA CONVERSATION]

NORA WELLS: Beth Doretski. She's going to talk about the Massachusetts partnerships.

BETH DORETSKI: So my name is Beth Doretski and I'm happy to be here today and I'll – because I believe in happy endings I actually have one to share with you that in addition to being Valentine's Day, today is also National Congenital Heart Disease Awareness Day and when my

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son was born almost 21 years ago we had been told not to expect to celebrate his first birthday and he will be 21 in April.

I'm mostly Zach's mom, that's my day job, and in my spare time I direct a project at the Federation for Children with Special Health Needs in Boston and I'm the project director for the Mass Family Voices project, which is also the site of the Family to Family Health Information Center. One of those centers funded by Maternal and Child Health Bureau. And I was going to give a quick overview of some partnerships at a system level, a Medical Home hospital level, and a statewide initiative that we're happy to be partners – like parent partners on in Massachusetts. I think in the interest of time I'm going to skip the system level one. Anyone that has – although I will say that one of the nice outcomes of that was we have a new behavioral health services in Massachusetts and there was some problem – there through our Medicaid program, there was a huge issue of access for families who were dually insured, whose children had private health insurance and were using one of our Medicaid programs as the secondary insurer to bridge the financial gap between what the private insurance paid and what their out-of-pocket payments were. In order to get these services there was no private health insurance paid. There was trouble with TPL, there was an issue with third party liability and it has never been addressed at the system level of what to do.

So I brought – we had a lot of – it's one thing to go parents are having trouble, it's another thing to go I have gotten a 102 phone calls this month about families that don't understand why they're being told that they can't access these services when their

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Medicaid eligible children clearly can have them. So I went to what's known as our Children's Behavioral Health Initiative, which is part of our executive services – Executive Offices of Health and Human Services, and said this is the data. These are the issues and this was the response. Thank you so much for passing this along.

So you can see the rest of the quote but the bottom line was they said, "I'm thinking we should also work on this from the parent end and forming an educating parents involved with –" and this was the Department of Children and Families to apply for Mass Health. Do you have any thoughts about that? And indeed we did and so we worked together to create a protocol. It was written to the regulations and part of what we do at the Family to Family Health Information Center was we developed a workshop about this that we do for – that initially was designed with families in mind, but at the provider end because they just didn't have enough information about how to actually navigate the billing issue, I've done probably more trainings for the community service agencies that are providing these services than for the actual parents. Although, I still do speak to a lot of them about how to access it.

So this is one case where I can say a measure of success was that people stopped calling – oops. Was that people stopped calling to complain.

So that was my measure of success for that. The other one that was pretty exciting was that we had a Medical Home hospital initiative in the state and it was a built as a collaborative care

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model for management of headaches. This wasn't specific to children with special health needs or behavioral health needs, it was just any child that was having a headache. And this was something that actually – a Medical Home practice identified the problem, they invited the Mass Family Voices project as a partner to sort of like designing the protocol and because there were private and public payers on board, this partnership actually came with money, which always makes the executive director of my agency very happy.

There was no standard of care for headaches when imaging was needed, when to prescribe meds. And the big issue, as some of us know really well, is that there's very little communication between primary care practices and with the specialty docs and the parents are sort of the go-between. At the neurology end, they had identified issues. They had very limited appointments for non-urgent headache care. There was a problem with access to imaging, well just to neurology in general and imaging, and there was an issue with follow up with neurology for stable headaches, which was very costly.

So this was sort of like trying to diet and lose – stop smoking and lose weight at the same time; they wanted to increase the quality of care but also decrease the cost. So they decided that – it was a Partners in Quality Initiative and it involved a Medical Home, the neurology department at a children's hospital, both private and public payers, and the Mass Family Voices project and we all worked together. This was also really nice. I don't know about in other states, but sometimes they bring the parent – they ask for the

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parent piece at the end and we were brought in at the beginning to really be part of the work team to develop the protocol and materials. We worked together to develop the family care maps so that people could move more seamlessly and that there was better communication between neurology and the Medical Home about making the headache diary. They actually had a start for that and it would be talking about the position and occipital and all the different parts of the brain, and I said, “Why don’t you just put a picture in and let the kid point.” And it talked about trying to assess pain and I said, “There’s a pain scale for that.” You know the little smiley face going to the frowny face. I said, “Maybe you should include that,” and they thought that was a really unique wow idea. So now we have a really family friendly document, which was very nice.

And so part of the outcomes there are – this is still relatively new. There are 24 people. There are 24 families enrolled in this study now and more and more are being referred to this model. It was very empowering for the families and the patients to be active participants in their care. It did indeed reduce unnecessary imaging studies. It improved coordination of care and it decreased costs. So those are all good things.

Then another thing is that because of the children’s health insurance program reauthorization one of the pieces of that legislation was that they floated money for quality improvement grants. And Massachusetts was one of the 10 states that actually received one of those grants and again they brought Mass Family

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Voices in at the beginning when they were actually writing the grants. So that was very exciting.

These grants are funded through the Centers for Medicare and Medicaid Services, Section 401D. I am required to say that. The grant is to the Massachusetts Executive Offices of Health and Human Services Division of Medical Assistance because they had to be the lead agencies for these grants. And there are lots of partners and I'm really proud to say that – Oh, and NICHQ, you now know what that is, and if you didn't before, and NEACH is the New English Alliance for Children's Health. That's one of the projects of community catalysts, which is based in Massachusetts as well, and the Mass Family Voices project.

So it was to – this is fairly new. The grants were awarded last February. It's still sort of getting off the ground but the goals are to improve child health care quality, identify gaps in child health quality, identify new and used full quality measures for consumers, include child health issues in the broader state activities, just sort of piggy-back it because everybody's working on their own thing and this was sort of looked at as an opportunity to bring everything together and really advocate for children's health issues at the state level and to ensure consumer education and transparency, which was another reason that they decided to bring in parent partners. Although I consider ourselves parent professional partners about it.

The other thing is that part of what the Mass Family Voices like a task on the work plan is to figure out ways to involve other families. And so there's a variety of strategies that we're using

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and part of it is to target parents where we know that it's already an interest. So our project receives hundreds of phone calls of month and a lot of times it's just we have a question, we need an answer and we provide that, but as we work with families we learn more and more about their issues. And so even broader than this project, like I was talking to a dad that had a single issue as far as access to services, but he had been doing this for a long time for his – on behalf of his daughter to advocate for her needs and clearly had a larger system-wide issue. So a school of public health was looking for a parent to be part of a panel to talk to one of their classes. I called the dad up and he was really pleased to do it.

So that's one of the strategies, is we try and note when people have a broader interest in something because we never know when there's a great opportunity to plug them into. And so that's one of the strategies that we use and that's a strategy that I'm using to help that I will continue to use as we speak to families and as there are other opportunities to get them involved in this CHIPRA initiative.

The other thing is that NICHQ, the National Initiative for Children's Healthcare Quality, is a partner on this grant and they are doing the Medical Home piece. And so one of the project tasks will be we need to recruit families to be parent members of the Medical Home teams at the 22 primary care practices across the state that will be chosen to participate in a learning collaborative.

And so I created what I hope is a fun and engaging Medical Home sort of primer around the CHIPRA legislation and included pieces

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of the Affordable Care Act that we can do to help recruit families and get them interested. It also really helps to be very clear about the opportunity, the expectations, the timeline, and if there's any funding to sort of help support their participation. The parent partner piece of the Medical Home Collaborative is going to be huge; it's a 27-month commitment, so it's really good I found to sort of lay all that out.

Then there are some other – I wanted to mention some family centered care self-test assessment tools that were developed by Family Voices with funding from the Maternal and Child Bureau. The thing that I really like about these tools and Nora has some paper copies and some on CD at the front, and if you don't get it here then they will also be available at the Family Voices exhibit table. But the thing that I like about this is that – I mean, in addition, one, it's broken down by principal of family centered care so that you can see that there's stuff about family provider partnerships, there's stuff about care setting. There are questions about care setting practices and policy. Is that it is one thing – and there's also a provider tool as well. There's no scoring. It's just to sort of figure out where you are on that family centered care continuum, but another way that I think is very useful for using these tools is that if you ask someone an open-ended question like what would you like to see happen, it can be very difficult to ask but if you go sort of question by question through the tools it gives people ideas like, "Wow! I didn't know that my primary care practice could be a place to connect to other community – where I might get information about other community supports that would be helpful to my child and family."

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Well if you have a question that says, “Do they connect you to community services and supports?” And it’s happening, you might say, “This is something that we could work on.” You could go to your primary care practice and say, “You know, these are places that I’ve used for my child and family, maybe you should know about it if other people are asking these same questions.”

So I do think that that’s another way; that’s it a really good idea to sort of jump start the conversation and say, “Maybe you’d like my – we have a lot of experience with whatever the issue is, can we do an in-service at what of your staff?” Maybe a suggestion box. Maybe you want a family advisory council. So those are all the sort of ideas and if you – you can also download these materials from the website, which is on the bottom of the slide. And that’s it.

Female: Thank you.

[OFF CAMERA CONVERSATION]

DAWN WARDYGA: Hi. My name is Dawn Wardyga and I am from the state of Rhode Island and, yes, that really is a state. Some people don’t think so but for a small state we do a lot of interesting things. I come to this work, first and foremost, as a parent and there seems to be a theme today about Valentine’s Day. Twenty-five years ago this morning I gave birth to my twin sons who were full term and over 7 pounds a piece. The second suffered a severe brain injury during birth and he was left technology dependent and medically fragile.

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We went through every nightmare you could possibly imagine in the 19 months we had him with us.

So needless to say, today's a melancholy call kind of day for me because as I celebrate my son Jeffrey's 25th birthday, we also miss the fact that Jason's not with us. But this is really what got me into the work that I do and again, first and foremost, as Beth said, my day job, my primary job has always been that of a parent. I do have other children, but it's really Jason and the experience of having Jason that brings me to this work.

I started actually doing this work as a volunteer within the State Department of Health shortly after my son's passing. And actually left a 17 year federal career to do volunteer work; my husband wasn't really happy with me at that time. But for the first time in my life I felt like I needed to do something for me. Luckily, he stuck it out and he's still my Valentine. So I wasn't quite sure that was going to be the case. But having said that, I started my work as a volunteer. I think moved into a parent consultant role within the Department of Health as they came up with grant funding to cover very part-time work. My husband was happy when that happened, not as happy as if I would have stayed with my other job, but that's beside the point.

I'm now the Director of the Family Voices program in Rhode Island, which is also Rhode Island's Family to Family Health Information Center and we're located at the Rhode Island Parent Information Network which is a larger and non-profit organization that offers several different programs and projects that serve all

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kids and families. Not only those who have special healthcare needs but kids and families in the state.

My example actually is a particular program area that we have that comes out of our organization and I'll give a little plug for the next set of breakouts is that what I'm giving you is a little smidget of information about that particular program. In the next set of workshops is a much more in-depth presentation that will include Rhode Island and I believe Nebraska, who's modeling a program after **** is Rhode Island.

So I'm just going to give you some quick background on this particular program. The program is called the Pediatric Practice Enhancement Project and of course we all love acronyms so you can call it PPEP for short. And what's before you, I don't think I have to read for you, but basically tells you what the mission is of the program. And many years ago, when I was doing this work as a volunteer often times we would say that we needed to clone parents to be able to do this work in the community. As the first parent who walked through the doors of our Department of Health, as a parent of a child with special healthcare needs, I'm not quite sure how welcome I might be in that setting.

To see today that we have this particular program in Rhode Island with the number of staff we have that are out stationed actually in community sites including pediatric practices and in-health clinics and that type of thing. It's just amazing to see – I sit in a staff meeting today and I look and I say, “Wow. They actually did that. They actually cloned the families.”

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So this project, what we work to do is ensure a coordinated system of care for kids with special healthcare needs. We work very closely with health insurers. We work very closely with policymakers in the state and basically these are 2009 accomplishments and milestones. I'm not quite sure we've established the 2010 so far and actually if you go to the session this afternoon. Lisa might even have some updated numbers.

We started out with 24 pediatric and specialty care clinics that we hired – the Rhode Island Parent Information Network, the non-profit organization, hired parent consultants, trained them, support them, and put them out in the community and we supervise them as well. For our 2009 accomplishments, when we had done some data collection, the annual – what our experience showed us, what the annual healthcare ***** were actually lowered by 15 percent. For those, it was ***** focused on kids with special healthcare needs. For those particular families who had the service of a parent consultant and a lot of that was around emergency room diversion and that type of thing. When they were better supported in the home settings, they would up less in the emergency rooms and so on.

Most of the time, when our kids show up at the emergency room, they get admitted. So we try and avoid the emergency room at all costs.

The PPEP was actually accepted and recognized as a promising practice in Maternal and Child Health by MCHIP within the last

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year. The PPEP's a Medical Home model and it's a team approach. Again, we use all the – for those of us that have been doing this work for as long and longer than me, we use all the terminology and we try to practice all the terminology. Clearly family centered coordinated comprehensive continuous compassionate. I think that should be a capital 'C' in that one. And culturally appropriate.

Again, I think we all in this room know what a Medical Home is and should be. What we built this program on was partnerships between families and primary healthcare teams and community partners. And we've worked together as a team to manage all the services and all the components to be better able to serve the families. The families don't really know the mechanics and as a family member I'll tell you the families don't really care about the mechanics. It's simply a matter of getting them what they need, when they need it.

Just some background goal information with objectives. Again, provided the coordinated care, improving access and awareness around communication with community resources. Someone mentioned earlier today about the fact that physician offices don't have all the information and they don't pretend to have all the information and they couldn't possibly have all the information and still provide medical care. So one of the things that as you all know is families who have been through this, we become very resourceful, whether that's for personal reasons or whether that's to apply lessons we've learned in the past for families who come behind us.

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There's a recognition that families with kids with special healthcare needs are critical decision makers. They're not the only decision makers, but they're critical decision makers and they should be part of the discussions that make decisions. Again, an increased understanding of the healthcare delivery system and access to community resources. We truly work as a team when we talk about the health policy at the state level and we talked about working with insurance companies, whether they'd be Medicaid or private insurance, we work with both. Not everyone plays nice, but it's just its part of the beast basically. We've come a long way since we've implemented this program.

You'll hear different terminology at different states. I started out as a parent consultant. We have now moved on to kind of shift that title to family resource specialist. All of these personnel there, they're family members of kids with special healthcare needs. So they've lived it, they've gone through it, their experiences are all pretty different from each other but together we work as a network and I may have a parent consultant or a family resource specialist working at one practice that comes up with a really challenging issue and it's mostly around social, emotional community needs and that type of thing. And we use our network within the agency, we'll pop a question through the e-mail list and 20 minutes later you've got 10 different suggestions as to how to address that issue. So they really work together as a strong network of family members who know what it's like, who have lived it and walked the walk.

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Our partners in terms of this is really the core component. There are a lot more partners with this project but these really – these are the partners that have contributed not only funding but obviously believe in the philosophy or ***** services. So the Rhode Island Department of Health was really where this got started. The Rhode Island Department of Human Services became involved later in the process. In our state they're the organization that manages Medicaid and once we got them to the table we were able to do quite a bit more because we could access the Medicaid funding.

Our Family Voices – we have a Family Voices leadership team and it actually acts as an advisory group to the PPEP project. So we meet once a month; we've been doing it since the beginning of the project and we'll continue to do it. And of course the larger organization, which is the Rhode Island Parent Information Network, which includes Family Voices.

Again, these are some details. It was developed in 2003; we were focused on Healthy People 2010 objectives. There had been 4,200; again, don't be surprised if that number's a little bit higher. I thought I heard somebody say it's about 4,500 now, families that we've served through the PPEP to date. The rest we've already talked about. And these are just some quick evaluation results and I'm going to provide you with some links to places where you can get much more detailed information about some of this outcome data. I chose to talk more about the program because Nora knows how much I love data but having said that we do have a considerable amount of data and if you use the links you'll be able

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to get that and get some of the details. But these were some of the high points, if you will.

Families reported out – well actually the numbers showed that 81 percent of the presenting problems – so these were issues that the practices couldn't necessarily deal with on their own and they referred back to that family member who worked in the practice to kind of troubleshoot those kinds of issues. Eighty-one percent, exceptionally high of those problems were resolved. These are problems that without having this component within those practices. Those medical practices would not know where to send those families.

Coordinated care. Again, I mentioned fewer health encounters. And again, those of us who have kids with disabilities we avoid the emergency room like the plague because we know that means an admission when our kids get there.

Lower inpatient utilization. It actually was 24 percent lower for PPEP participants compared to – we had done it before and after kind of sampling – and it was 34 percent lowered compared to kids with special healthcare needs who were in standard care. So in a practice that didn't have the support of a family consultant within that practice and lower patient costs. Everybody likes to hear this one.

Annual healthcare costs were 39 percent lower for PPEP participants compared to those before the PPEP and a 27 percent

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lower compared to children with special healthcare needs and standard care.

These are – people don't write them down because you'll have access to the slides – these are the different sites that will give you very specific outcome data and obviously this is a work in progress. We continue to update these numbers and the contact person, I'm not Colleen ****. She's one of my partners who works at the Rhode Island Department of Health and she manages this program from the Rhode Island Department of Health perspective.

Sustainability. Quickly, we always have to talk about creative funding; that's what we've done all along and so far so good. We are beginning to get buy-in from managed care plans and private practices in other community sites. So we'd hire a parent consultant for a certain number of hours and that would all be through our funding and then they might match us after a certain period of time.

Once they've established the credibility of that staff member, they figure out ways how to contribute to that. And when we say our funding is threatened, they're like, "What do we have to do to help?" So they certainly don't want to let go of that staff member.

That ends my piece. I wasn't sure if –

Female: I had a few – very, very few observations to make, first of all. We kind of went from a very particular setting of a model of thinking about the

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quality and what it means and how to improve it to a very specific setting within a hospital and what went on there to help change things to a broader thinking about quality in many settings and thinking about it not only in the specific care of a particular child in a particular instance, but in the ways families receive care in a more systemic approach and how we begin to think about quality partnerships that can help there. I think I'd love to hear from the audience other questions for any specific or in general.

Yes? Susan.

SUSAN FOLEY: Susan Foley from the National Center for **** Abuse ****. Thank you so much for the presentations. It was really very, very eye opening and I'm wondering what you – you're looking at your outcome of costs and you mentioned – you showed it was reducing healthcare costs. Have you looked at whether it's reducing cost to families like things like job loss or earnings lost or anything like that? Is that something that you're focusing on?

Female: Back to my favorite topic of data. We are constantly updating the amount of data and the type of data that we're collecting. We also work closely with the Catalyst Center and those are some of the numbers – those are some of the things that we want to get a better handle on. At first we wanted to really establish that we knew in our hearts that this was a good thing to do but obviously we can't do anything without the data. So we've been working on actually establishing the credibility of the program, if you will.

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But some of the cost numbers that you'll find in some of those links that I've provided with you have come right from the Managed Care Organizations and that type of thing. Those more broad questions about impacts on the families and out-of-pocket expenses and that kind of thing is not anything we've looked at to date but it's always on the back burner. Just when we get our staff all settled with the data we want them to collect, we change it. So I think we've learned from the Feds on that.

Female: Sounds like an excellent area that we'd like to continue to collect information on. Other questions? Thoughts? Yes? Please identify yourself as Susan did; that would be great.

Debbie: Oh, sure. Hi, I'm Debbie **** from the Maryland Office for Genetics and Children with Special Healthcare Needs and I have a question actually for both of the programs involving parent partnerships both with the specific example **** on neurology **** doctors and the PPEP program. Are the parents able – one of the difficulties you mentioned I believe was the primary care doctors and specialist don't often communicate very well with each other and parents are left to be the go-betweens. Do the parent consultants or does the model in the neurology example help with that with improving doctor-to-doctor communication?

Female: The family's still sort of the go-between.

Debbie: Go-between.

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Female: Because they have like care maps now that ****, but to address the needs of health literacy and families that didn't always know why they were in a particular place for a particular visit it was all mapped out and so yes.

Debbie: Yes. So it was a written plan that the family's shares?

Female: Right. And I actually feel very strongly. It's a personal bias of mine of not taking families out of that equation because especially if your children are younger. If you don't model sort of the communication pieces that your child's going to need to take responsibility for their own relationships with their health providers and to sort of learn to ask the questions that they're going to need to do and to be clear about the directions that they're giving you and what the follow up might be, who is going to teach it to them. So that's a personal bias of mine. But also because the Medical Home practices is sort of like a Medical Home site of the hospital. They're working on an electronic medical record health information exchange pieces as well that will view the doctor-to-doctor link but for this particular thing we felt it was very important to sort of keep the families there but give them easier access to the information and a way for them to better understand the process for families that were maybe new to it or just – because think a lot of families with children with special healthcare needs are kind are – it's more ingrained in what they do every day and this was a model that – I mean any child could have headache issues and that **** tension **** when do you know what to do.

Female: I think –

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Female: The response on the PPEP side of that. I will just say that the staff that work in those settings, they really wind up doing a lot of the coordination that does connect physician-to-physician but what they also do and what they really focus and the model that we try and promote as much as possible is a mentorship model so that those parents can pick up those skills from that peer support person and at some point in time be able to take it and run on their own. That's really the model that we practice.

Female: Pat, did you want to make a comment?

PATRICIA HEINRICH: I was just going to mention that NICHQ has done quite a number of projects with this including funded by the Maternal Child Health Bureau to Medical Home. **** year-long collaboratives and epilepsy project, the project with following children with hearing loss, and they've worked to help facilitate that communication between primary and specialty practice with tools like fax back forms, but one of the things that was most compelling was a care notebook that families came up with the idea and began and some of the teams has I think a widely adopted by many places working with families to – with children with special healthcare needs and we even had an example in our epilepsy project that because a family member brought a copy of a CD of an MRI, it might have been a CT Scan, I think it was an MRI, to a hospital emergency visit while they were on vacation. They were able to prevent the needing to have that test redone on an ER visit in a different state or place that they were visiting.

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So there's been a lot of effort and there's ongoing effort; we're still working – the NICHQ is still working on many of those things but the other thing I think is great is that the Accountable Care Act is going to actually have legislation. The doctors are going to need to be able to communicate with each other and it starts slowly. It's not happening this year or next year but and it will start slowly to be implemented, but those systems will be more available in an electronic communication between one doctor and another.

Female: Thank you. Yes? Right here in the pink skirt. If you could identify yourself please.

Female: **** Maternal Child Health Bureau. I wanted to ask Pat and also other panelists whether or not they thought that electronic medical records was a good data collection tool to see quality improvement or how can it be shaped to observe QI efforts.

Female: Well I can tell you that there are a number of different electronic medical records and like public health departments you've seen one, you've only seen one. There are not exactly all the same and right now they don't talk to each other and right now some systems in them don't talk to other systems even within the same organization. But I've also – and many electronic records are not patient databases. So when you're trying to improve care for a population, you really need to have a way to look at not just the individual patients, which is important, but the population that you're trying to serve.

So there are electronic records and systems in place that do that. I'm working on reducing disparities with a number of

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organizations in California through the University of San Francisco – University of California, San Francisco, sorry. And they've got a database. They call it I2I and that population base capacity to review and they have individual patient information and those work really quite well but as I said not all electronic medical records do those kinds of things and I believe that the research actually shows that electronic medical records in itself does not improve quality.

Female: Other comments from the panel? Terra or Beth or Don?

Female: The only thing that I will say is that I think that's an ultimate goal. I think we're very far away from that. I think that this is one of those things that it will be a gradual process and at least from a family perspective and a family advocate perspective, I think that if we can get electronic medical records to emplace that when I go to the emergency room or go to a new provider I don't have to repeat my story 22 different times then I'll feel like we've really accomplished something and if there's some type of electronic and again it brought up that something else up this morning that do people actually look at them. So we can do all we can to put that data in and it can be really good data but if the provider is not reviewing that data ahead of time, they come to the bedside and they're asking those same questions that are in that database. So measuring outcomes I think that that's a great thing for us to be thinking about but I really think we need to focus our energy more on making these systems ****.

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Female: Well I know there are folks working to develop something that will sit on top of your electronic medical record that will – it's been this many nights since this line was changed and kind of line a pop-up goes up to tell the provider a decade after that or whatever it will be maybe the patient or family members can get an e-mail at the same time that that provider's getting that pop-up to come up to let them know that it's an issue too. So I think we're going to see so many changes in the coming years in terms of how we can use electronic data to better engage both the providers and the families.

Female: And Terry, you're bringing up I think a wonderful point which is the point of this session really, that's the partnerships between the receivers of the care and the providers of the care and the community in which the care is context in which the care is given that's going to help us improve quality. So those initiatives which think about ways that we can engage all the partners I think are really critical.

Okay, Josie, yeah.

Josie: I guess I just wanted to bring up, as a parent of a 38 year old child with special healthcare needs and was also developmentally delayed, that I would hope soon we will have individuals with special needs themselves as consultants. I mean this especially for kids with ED in women's health and especially breast care, mammograms, all this kind of stuff because in our state actually fastly is becoming a peer is just a peer. Because she's had to go through some of these experiences. So she actually interacts with the young women who need – who never had a mammogram or the table doesn't go down so they've never had a ****. So as parents I like the idea of

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making sure that our children know the questions to ask, understand them, and wait for as long as they need to get the answer that they need to have. I mean, it's one thing for us to do it but we won't be here forever. And then we have to look more broadly and for **** not just parent consultants but peer consultants.

Female: That's a great –

Female: Thank you, Josie.

Female: The Spina Bifida Project that NICHQ did in partnership with the Maternal Child Health, that was a great example of that project because as we have new technology in health care, we're saving people that doctors don't know what to do with them when they get older. So we had patients there as partners and it was so powerful because when the Spina Bifida Association and all the expert doctors were saying, "Well we don't have any data and we don't, you know, we'll have to collect this data." The patient's said, "Well, what do you mean you don't have any data? I'm right here! Use me!" So it's exactly that. And those people helping doctors know what they need.

Female: We have two minutes. Don't worry; there's plenty of lunch. Is there any other question in the audience? It looks like we have two questions here. Sorry.

Female: **** from Utah Department of Health. Thank you for your presentations [INAUDIBLE] pearls of wisdom. One area – not really a question that I'd just would really to emphasize and interested in perinatal

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quality improvement partly because **** perinatal ****. **** pregnancy but I did want **** and what we've seen over the years is maternal deaths among women who have had chronic conditions repaired relatively healthy and then become pregnant and are not **** appropriately during their pregnancies. So just a shout out to – we're looking for funding **** BQI in Utah more in the perinatal realm as opposed to the child health realm. That's our **** in Utah, but a critical area **** love to talk to you after the presentation.

Male: They said you only had a limited time because we have to get the March of Dimes for us to hold our regional meetings that are scheduled for ****.

Female: Okay. Thank you everybody. Well we've enjoyed having you. Thank you.