

2011 AMCHP and Family Voices National Conference: Families as Agents of Change: Building Infrastructure and Systems for CYSHCN

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

LYNDA HONBERG: **** healthcare needs. My name is Linda Honberg; I'm going to be moderator for today's sessions. I'm also the Deputy Branch Chief for the Integrated Services Branch within the Division of Children's with Special Healthcare Needs in the Maternal and Child Health Bureau. And the Program Director for an initiative we've been doing and you'll hear about for several years, since 2005. and unfortunately one of our presenters, Nancy Casen from John Snow, who I've also been working with came down with the flu and over the weekend kept saying, I'm gonna try and come. And I was like, no what? Leave your germs you Boston. And we're sorry that she can't be here. She's really a great partner with us. But I am very familiar with the program and we'll be doing her presentation.

With us also today are actually two people who have been funded with this initiative, Josie Thomas, who I've been told needs no introduction, is the Executive Director of Parents Place, and actually just a small aside, the other hat that I wear is that I am a parent of a young adult, I have to get used to saying that, with special healthcare needs. And when Sara was born many years ago and I was trying to get information, I remember people saying, you should go to Parent's Place. It's a great organization. So.

And here she is now a freshman at the University of Maryland. And on her road to advocating for other youth with special healthcare needs. So you'll be hearing from Josie about her project and the role that families have been playing.

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And also is Deb Garnell, she's the Title V Special Needs Director for the Rhode Island Department of Health and in that position, he's responsible for the supervision, management and partnership of the office's three programs which include pediatric specialty service, disability and health and family support and empowerment. And he'll talk a little bit more about your office too in your presentation.

So with that, I also have been told to let you know... I'll turn the page here and put my glasses back on because the older I get the lesser I can see... is that this session is accredited for continuing education, which is why you are all here, right? And that immediately following the conference... has everyone heard this many, many times again? So I don't need to say it again? Great. Make sure that you fill out your Conference Evaluation because obviously that's very important in terms of making the program better.

So with that... and what am I doing wrong here? Okay, thank you. So I hope this is all familiar to all of you in the room that we have these six performance outcomes that we use to measure a system of services for children and youth with special healthcare needs. And I actually like to say that... and use the language that Polly Orango said, which is, these are our promises that we've made to our families that these are the... that this is a type of a system, their children and youth will get that first and foremost that families are not only decision-

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makers at the individual level, but also are decision-makers and are agents of change at the policy and program level and they're satisfied that the services that their children receive that obviously access to a Medical Home, that there early and continuous screening, that services in the community are easy to use, financing is adequate, and it's more than just a health... it's more than just health insurance because I think we know that there's a lot more services that children need than just insurance, and that the ultimate outcome that there is transition into adulthood.

And a lot of times when people see these outcomes, they view them almost as separate silos. And I just want you to leave with the understanding that these are all interlocking pieces of a picture and that without one of these, you don't have a complete picture. Sometimes in terms of changing a system you may want to focus on one, but no matter which one you focus on, it leads to the other ones.

So we're going to talk a little bit about this initiative, which has actually gone through a lot of name changes. I think I'm going to have a contest, Name this Program. For now it's a state implementation grant for system or services for children with special healthcare needs. And the reason we focus on the state implementation is because prior to 2005, the Maternal and Child Health Bureau actually used to fund demonstration grants that were focused on each of these performance grants. So for example, we had a number of grants that just focused on

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Medical Home. We had a number of grants focused just on health insurance and actually at the time, they were focused on managed care.

And what we found when we looked at those grants is, as I just said, that no matter which performance outcome they were focused on, they involved the other ones. So if you want to improve Medical Home, you're going to obviously have to have families and they're going to have to be decision-makers and they're going to have to be advocates to make sure that Medical Home is working.

That to be a Medical Home you have to have access to easy to use services, that obviously financing is going to come up, both in terms of the services provided through the Medical Home, but also things like you know, making sure that families have insurance and financing for the other services, that where else but the Medical Home do you provide early and continuous screening. And then obviously, within a Medical Home, we know it's not just young kids that there are going to be older children that are going to be transitioning to adulthood.

So we, in 2005, shifted the focus to fund state... entities within the states to work on the total system. It was three-year budget periods at \$300,000 a year. We've had four funding cycles to date. I call them the class of 2008, so they graduated in 2008, and you can see the number of states that were funded. We are having a new competition, actually

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applications are due Friday, which I have been getting a number of frantic calls.

And with us today, actually, Deb Garnell is from the class of 2009, and Josie is from the class of 2011.

So what we found out about the grant **** is that all states had received what we call SPRNS Grants, that's Special Projects of Regional and National Significance. And that really provided some base of funding and infrastructure building for the states. So far, we've funded 34 states, the District of Columbia and the Navajo Nation. Most of the grantees are, have been housed within Title V, but we have three Family to Family Health Information Centers, and Josie is one of those. And obviously Deb is one of the Title V, but we also have some that were housed within University's hospitals or the local chapter of the academy and then again the one tribal entity being the Navajo Nation.

So this is a map of the states that have been funded. Our goal has always been to fund one of these grants in every state. So we are having the competition for this year and we'll have one more competition next year, which will be the class... I 'm starting to lose track, the class of 2014. And then that'll be it.

We're actually involved in envisioning 2020, some of you might have heard about that. And we'll be doing our strategic planning about next steps.

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So let me talk about some key things from these grants. First, for the most part, most of the grantees use Medical Home as a cornerstone and a launching point to improve the system in their state. And again, as I said before, the existing infrastructure and strong partnerships were critical to success. And we like to look at it as kind of the three legs of the stool which is required to support the system, that being Title V families and providers. And we've been actually thinking that it should really be a four-legged chair because Medicaid is so critical and certainly with healthcare reform, it makes it more important. But unfortunately, when we look back at a lot of the funded, previously funded grants that oftentimes Medicaid wasn't part of that chair. And the other thing is that we find that sustainability isn't easy, which is why partnerships becomes even more critical.

These strategies are based on an analysis we did of the Class of 2008, so from the previous map you saw we had 12 states that were funded. We actually got, finally, reports from 10 of the 12, and actually in two of the states we didn't get final reports because that partnership building had fallen apart. And so when we looked back at the states that had been previously funded, we saw the strategies that we thought contributed to the success of moving the system forward, which is one using continuous quality improvement and oftentimes that was through a learning collaborative. And for those of you whoa re

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not familiar with that, if we have time we can talk about that a little bit later.

But basically it was a commitment to use quality improvement as a way with all the partners using data to build capacity and measure impact. Many of the states provided technical assistance, resources and system supports. So either, for example, providing TA to their practices who wanted to transform to a Medical Home. A number of states promoted legislative and policy changes. And I'm going to go a little more in detail in each one of these.

And then the last two, really, I can't emphasize it enough are the critical strategies, which is building and enhancing and maximizing your partnerships, and as part of that, engaging families and youth as partners/leaders and really the agents of change. And there's a real difference between say, you know, I have a family member and they're on my committee, versus, not only that, but I understand the families, they're there, they will always be there. And they are the drivers of change.

And then this last one was actually something that one of the current grantees suggested as something that they're working on, so I just bring that up, which is using social marketing to raise awareness about children with special healthcare needs. And we have gone back and looked at that, that a lot of the grantees did engage in activities to make stakeholders in their state understand the needs of this population.

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So in terms of using quality improvement, and I'll run through these quickly. Again, most states used a learning collaborative and they focused on Medical Home. Some on transition and screening was really a good mechanism to spread Medical Home and it was a good way for partners and a group of people to really exchange information about what works and what doesn't work. And again, an opportunity to engage families as partners. And I think that the biggest factor between what made one more successful than the other was using data. That some of the learning collaboratives were just more information exchange and didn't have data to measure change.

Using data to build capacity, one state actually had quite a data warehouse that they used to really measure change and really develop their program.

Providing technical assistance, almost everybody did things like conference calls and webinars, some used Telehealth, a number had a champion physician who in turn went out to different practices and did site visits. Mini grants to communities which actually Josie did.

Curriculum for providers. One state actually had a training institute, and then actually placing care coordinators in medical Home. Sometimes families and you'll hear about that from Deb.

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So this **** is really kind of the ultimate in system change. If you can have a legislative or policy change, it really offers the greatest potential for impact and sustainability. In just two examples was Oregon that actually got legislation passed. It required the private insurance companies to provide hearing aid.

And then perhaps many of you have heard about Minnesota. They've had a lot of learning collaboratives around Medical Home and the state legislature put that in their legislation. They call it Healthcare Home, but it's really very similar to Medical Home.

So then, of course, building, enhancing and maximizing partnerships that as, again, my theme is this is so critical for sustainability. It's really... it secures institutional memory. As I said, we had some states where the partnerships weren't that strong and so now there's... there was nothing to sustain because the partnerships weren't there. So you've got to have a history working together. If you haven't started working together then start now. And again, partnerships are not built overnight.

So then the last thing, and the reason we are here today is really engaging families and youth as partners. And we did see different levels, so you know, obviously, having key partners involved in writing the application. And actually, and I'll be interested in your feedback too, but many states have told us

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that actually writing the application started really cementing those partnerships. You know, having youth advisor councils and having family liaisons in medial practices.

The challenge was always retaining families due to time commitment, coordinating schedules around youth, but a lot of strategies did work in terms of having things like childcare and adjusting meeting times and locations.

So these are just four examples, and again, every state really engaged families, but I just want to highlight Massachusetts actually had an institute where they brought in families and framed them and then placed them in different locations throughout the city. And maybe Ron can, if we have time, he could talk a little bit about that and just... you know, unfortunately, there wasn't continued funding for that, but perhaps at the end of the pro... you know, while we're having discussion we can talk about it.

And then in Hawaii, I love this because families were just so infused and in fact, the name of their project was to ****
Firmly. And families were there all the time. And then the two presenters that we have today; and I'm going to let them talk about how they engage families, really to be agents of change.

So with that, I'm going to turn it over to Josie.

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JOSIE THOMAS: Thanks. I think I'm going to have a problem seeing over this. I think you can just see the top of my head, right. Can you see me? Okay, I'm standing tippy-toes.

We applied for this grant each time it came around and got turned down. We got turned down twice, and finally on the third go-round, we were successful. And the reason we were successful is because the first two times our Title V children with special healthcare needs program was not engaged and not interested. Which is the tale I'm going to tell you.

So finally, we were able to partner with them more fully and we wrote the grant together and that really did begin to cement that relationship. What happened is, that initially the state was going to go in as the lead agency, but because they could not get contracts out as easily as we could and their procurement process required them to go through a competitive bidding process, that would not have worked for the way we had developed this grant because we had sub awards for the AEP, we had... there would have been a sub award for us, there would be sub awards for other folks. And that just wasn't going to work, so we shifted it around and we became the lead agency... the lead applicant.

And you can imagine the kind of letting go and negotiation that we had to do to have everybody feel comfortable about this. So, we initially went in with... we've added some partners; it was the first four partners. It was the Parent's Place of

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Maryland. We serve as the Family to Family Health Information Center as well as the PTI or the Maryland Family Voices affiliate, our Title V program, Johns Hopkins School of Public Health, some of you know Holly Grayson and Cynthia Minkovitz, they were doing the... they do the evaluation for the project and the Maryland Chapter of the AEP. We added... as things changed, as I'm going to tell you, this was the incredible changing project.

We added a Johns Hopkins School of Medicine and Maryland Healthy Kids, not Health Kids, which is what our EPSC program around developmental screening. We had four initial goals was to build the infrastructure and the leadership to develop a community-based system of care, something that in Maryland just has not existed. To improve developmental screening our scores on the 2006 **** National Survey were very low. And our state AEP survey showed them to be even lower. So we really wanted to go in and make sure there were practices were implementing developmental screening. We wanted to improve access to Medical Homes and we wanted to increase the focus on children with... in transition.

We kicked it off with a two-day summit with broad group of stakeholders because one of the things we discovered in Maryland is that Title V Children with Special Healthcare Needs just is not on anybody's radar screen. Nobody knows about this program and frankly our kids aren't on anybody's radar screen.

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So we pulled together 120, 150 people from education, mental health, community-based providers, Medicaid, just everybody we could think of and invited them to come... and I think you came, didn't you? And we worked in small groups to focus on the six core outcomes. And we used that to kick off our work.

Within two months, well within two... I'll get to that. So that our purpose was to build a group of stakeholders that could really help build that vision for children with special healthcare needs in the state. And frankly because folks didn't know about children with special healthcare needs and the program, we needed to do a ton of education which we did early on. Just about every single meeting, we did a ton of education. We brought people in.

And we wanted to provide input and advice to Title V children with special healthcare needs; they were working in isolation in a very antiquated system. I'm gonna... yeah okay... where am I? Okay. I'm sorry; I just wanted to see where I was.

So the consortium is again, the group of very active stakeholders, we get between 35 to 55 people attending these meetings. Every time we send the notice out, we say, I don't think anybody's gonna come. And they come. They come. And we scratch our heads and we say, why are they here? But we keep hearing over and over again. This is the only place where we can talk about these things. This is the only venue we have

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for sharing about the work that we do together and we make sure that every meeting that folks are learning something, but they're also providing feedback. So it's not just a receptive sort of meeting.

We could not have done the Title V Needs Assessment without them because what happened two months after we had this summit, everybody in our children with special healthcare needs program left. So we had 1.1 or 1.2 FTE dedicated from their staff to this project and they were all gone. And the one person left was the Director who considered what we were doing social engineering. So, she's gone now.

So we were just stunned. And I called Linda and I said, "Linda, I have not clue what we're gonna do. I don't know that we can do this grant." And that was a pretty scary thing for me. You know, I just was really committed to making this happen. We had applied and applied and applied. And we had all these people interested, and we didn't know how we were going to do it.

Well frankly, our partners jumped in. Our partners jumped in, we took... at one of our meetings, we took a look at what had we promised that what we'd do and everybody had divided it up and said, okay, there's a void in Title V, Children with Special Healthcare Needs, this is about our kids and about us and we can make it happen. And we kept on going.

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And the mini grants go to communities. It's required to have parent involvement. And it can be on any one of the six core outcomes that folks to implement. There's \$7,500 for the year. And I'll tell you, we've seen some phenomenal work happening at the community level. It's a nice chunk of change. It's not a lot but it's enough to get something started and we're seeing some pretty innovative stuff.

One of the ones that I love is the partnership between pediatricians and mental health providers in rural areas trying to get access to mental health services for families in those rural communities. Especially in community health centers, which was something that wasn't happening, but \$7,500 was enough to buy software for laptops so they can do telemedicine, they can do consults through Skype or whatever, they're using. I don't know what. But it's made a huge difference; it's money folks didn't have.

And the **** that's really interesting in that piece is that we're the third leg of this so that when a family comes in and need mental health resources, community-based resources, not only do they get the link with the mental health provider, the primary care provider also links them to us so that the family then gets connected to the community services. So that's been really fun.

A lot of the people that are in the consortium cannot do legislative outreach, but we can. And so we identify priorities

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and we then get to be the face for this. And other folks are protected.

Hopkins has been looking every year at... been doing measures about how has it increased partnership. And so we've got a tool that we use every year. It's really interesting to see the changes happening. And the Needs Assessment process was phenomenal. I'll tell you that, there was nobody there to do it; it was a grad student and us. So we used our consortium, we used them for the stakeholder meetings, we helped them... we had them help us do our parent survey. You were there the day we reviewed the parent's survey. Took it... tore it all apart and talked about how to approach it, how to do the approach. And it was a pretty good process.

Developmental screening has been the most exciting thing we've done. We had a subcontract to the AEP to do regional training for pediatric practices and our target was, I think 500 or 600, and we hit 450. But in addition to that, we've really taken a look at some work that Tracy King from Hopkins was doing, and her data showed that without some hands on help, that implementing developmental screening wasn't very successful.

And so we used some of our funds by reallocating some of the money and providing it to her and we hired a part-time consultant from Reach Out and Read, so she does Reach Out and Read and she does this. And they go in and work with the

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pediatric practices intensely. Andrea goes in and she takes a look at what the flow is like and what folks are doing, ties it into Reach and Read, and helps them build a system for implementing developmental screening. I think if you take a look at screening training, that there's a huge drop off in the implementation. It's just tough; you're asking people to do things differently.

Prior to this initiative, we had managed to work with a legislator to raise the reimbursement rate for Medicaid developmental screenings and to add the 30-month screening so that we had them through an 18-month and then a 30-month and that was paid for by Medicaid.

Then you know, things kind of grew like topsy, you know, upside down. Our EPS/ET Director retired and she loved the developmental screening work because she had been participating with us on our work group, and said, "I'm retiring and I need a little bit of money. How about if I work for you as a consultant and I do outreach to family practitioners?" And that's what she's doing.

And so, I don't have the numbers here, but she... it's been tough. They don't want to talk to us, but she does... she's pretty persistent. And she gets them finally to let her come in. She comes in with dessert and a one-hour presentation to at least get them some level of awareness around developmental screening.

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Maryland selected six... identified six screenings that they would pay for under Medicaid. There's two that are preferred, but she carries the ASQ around, Ages and Stages around. So that's been very helpful.

And now we're looking at a family initiative. One of the barriers that we're running into is that families don't understand that their kids need screening, especially in Baltimore City where we're doing the bulk of our work. And families don't want to have their kids screened, so we're looking at doing a grassroots effort using some of our family leaders from Baltimore City to talk to other parents.

So one of the things that we're interested in is, are we getting increased referrals? So we're going to be tracking that is coming here because the trainings are all conducted with one of us present so it's done by pediatrician, one of us and then we get somebody from early intervention.

So, as I said, we had changed priorities. We had to kind of restructure what we were doing, and where things what you were going to get to. And so the focus has been really on doing what we did really, really well. And I talked about this a little bit.

So, I think we got Willy Wonka's chocolate ticket because it was time to do the state five-year priorities. And there was

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nobody there to tell us we couldn't. Remember, there was a grad student and it was us. So we took the Needs Assessment, we looked at the parents survey and reset, well by golly, we need... these are the priorities we want to focus on for the next five years and they are, as you can see, transition, which was a huge issue in our state, sustaining strategic partnerships through the consortium, it's written in their as a state priority. And the other is data systems and data sharing because we want to be able to document further what's happening with developmental screening and were really struggling with that.

So like I said, there was nobody to tell us, "No." So we run it in their and the powers above us said, okay, because they didn't know any different.

So I talked about this earlier, I mean, for us it's a huge issue as family organizations and change agents, but we have to be there. You know, I always say to folks, you're not the one the lottery if you don't buy a ticket. So we have to make it happen.

Relationships and partnerships is what kept this grant going and moving forward and really effecting change. Now that we have new leadership in place, it's phenomenal. Not only are they fabulous, but they're thrilled that they have all of this in place to help them move forward. We certainly had to be very flexible, thank God for Linda as a Project Officer, who is just as flexible and has understanding, well okay, what are we going to do now? We had to be responsive to the changes that were

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happening and trying to make it work and very insistent that this was not going to change.

When the director that was left behind was pushed out the door, there was nobody then at that point. And we were very concerned that the Title V Children with Special Health-Care Needs program was going to get dismantled. Very worried. We talked with the consortium, I don't think you were at that meeting, and it was probably a good thing. And we talked about what we need to do. And we scheduled a meeting, so two of us little parents going up there to meet with the big boss, okay. And we said, you know what, this isn't going to happen, you're not to make it disappear. We've got a plan for you. Here's a plan for how we can make it happen. And, you know, they liked it. And they went with the.

Suddenly developed a Transition Committee that met over time and to look at what Title V Children with Special Health-Care Needs were doing in we're doing quite well thank you. Things have really moved. But we felt that without the partnerships, we couldn't have made that kind of change. We had the creds; we worked really hard at it. So, that's us.

LYNDA HONBERG:

Thank you. When you're ready ****.

DEB GARNELL: Okay. So the Rhode Island... with our D70 Grant, we expanded a project that we have had in place, which is the Pediatric

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Practice Enhancement Project. We started it in 2004 Emily received The D70 Grant in 2006. And so we started out in 2004 with eight practices and we were able to expand to 25 practices through the use of the federal grant award. And so what happens when the Pediatric Practice Enhancement Project is that we employ parent consultants, parents with kids with special health-care needs, and replace them in pediatric settings and so we place them in primary care, and also into specialty care sites, and throughout our state. And so they work as Care Navigators, link families up with needed resources, doing a lot of the Family to Family Health Information work except actually at pediatric sites, not in a centralized office.

And so we, you know, we're really able to expand this model and to look at some of this sustainability of the project through these grant funds. So, it's definitely, the PPEP is definitely Medical Home because it's in the pediatric offices although a lot of what they do is a variety of work around education and mental health and linking families up with lots of basic services that they might need.

And so we have a list of some of the partners that are here, our Rhode Island Parent Information Network, which usually we always do anytime we talk about this project, we talk about it together and we actually, we're going to have **** do this with us as well from the **** Rhode Island Family Voices, but wasn't able, you know, as another session at the same time.

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Female: So as we speak.

DEB GARNELL: Yes. Yes. So basically we completely demonstrate constantly that it's a huge partnership that the state can't do it without the family organization in the family organization can't do it without the state partner and to have the successful collaboration that we have had in our state. And we have other partners where, the Department of Human Services has funded the project from the beginning, Neighborhood Health Plan is our Medicaid Managed Care program within our state, and so Family Voices we only have one Children's Hospital in our state and so they are our partner. In our local pediatric sites, and we have all of the different practices that we have been working with.

So I gave a little information about who a parent consultant is, you know, that just kind of says...

Female1: Want me to talk to that? For the 75th anniversary, The Catalyst Center made a video of some of what happens within the pediatric practice projects, so anyway we thought we would you show that rather than talk about it. ****.

Female2: And I think this is a good example... Oops...

[BEGIN VIDEO]

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Female3: I gave birth to twins at 26 weeks, that's very, very early. I was in this instant role of not just a mom, but a mom of two. And two were very tiny and had all of these problems. We spent three months in the Neonatal Intensive Care Unit. One of my sons was on oxygen when he came home. Everything spiraled out of control. Siobhan help me through those early days.

Female 4: So like Laura's twins, my son was born at 26 weeks in my life completely changed, that experience made me realize I could support families the way that I needed the support. I became a parent consultant. Basically what we do is empower families to be their own advocate. Where the family support helping them navigate community resources, advocating for them, and giving them the tools of educating them to be an integral partner of their child's care team, but most of all, we listen. Sometimes the parents need someone who has been there who can say, "Let me listen to what your needs are."

Female5: My son, ****, suffered a brain injury at birth that has left him with severe physical and mental disabilities. I was completely overwhelmed and the staff referred me to a parent consultant who has a son with cerebral palsy. When she first called, all I did was cry. It was just a huge emotional support to have somebody who has been there to understand where you're coming from. Finally she said, "how about I set you up with a support group?" I can say in hindsight, her knowledge of where I was at the emotionally, her patience and persistence in

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getting me into a support group went a long way to help me except when I had to deal with.

Female6: In 2007, we were fortunate to add Amy, a parent consultant to our staff.

Now what has been most surprising to me is that parents will share certain information with another parent that there is somewhat reluctant to share with a professional. In one instance, a child was having some breathing problems, it was the middle of a cold winter, the physicians said to the parent, "why don't you take the child initially into the bathroom, turn on the shower, turn on some real hot water and sit in the seat for 10 to 15 minutes with the baby to see if he improves." And the parent said, "Okay." Then the parent consultant came in and the parent then told her, "Our hot water was turned off a couple of months ago. We haven't had hot water for a long time." Well, the parent consultant submitted a request immediately to the utility company, got the physicians signature, got the gas and hot water turned on. A successful story. Actually it's been quite a learning experience for our team. During team meetings every other week, Amy will bring up any family circumstances that might impact care, or she might call our attention to a new resource in the community that we can all use. Now we're looking at the whole picture of caring for a family. I have to say, we've decreased the re-hospitalization rate in the first four months after discharge from the ****, the most vulnerable time for these babies. Our families really trust Amy; it would be wonderful if every practice could have a parent consultant.

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Female7: We started P-PEP because there was a disconnect between where people were going for help and where services were available. A lot of families were asking their physician for help with equipment or housing or education or other community programs and there were few physicians who are committed to this population who felt disconnected from the larger system of care. So we met with our partners and started a pilot and eight sites. We put trained parents of kids with special health-care needs in physician's offices to link the families to resources and services.

Today we have parent consultants in 24 sites. They've served about 4200 families over five years. It's been very successful. Families feel more confident taking charge of their children's care and we've heard from doctors that for the first time they can ask, is there anything else I can do for you without being afraid of the answer.

It's also proven cost-effective. Since kids participating in the P-PEP use in patient and emergency services less as their care is coordinated. For a state leader, the P-PEP provides a way to hear how programs are impacting the community and how you can improve upon them. Having a direct feedback loop from families ensures that your state is meeting the Title V mandate of making it easier for families to access services.

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When you look at the six core elements of a system of services for children with special health care needs, whether it's parent's professional partnerships, Medical Homes, transition to adulthood, community-based systems of care, early screening or making sure kids have adequate health insurance, P-PEP encompasses all of those areas. And it really empowers families to be active members of the healthcare system.

Female8: The program really tries to address values for families making it easier for families to connect, making it easier for families to have the right and appropriate and adequate level of care that they need.

Male1: P-PEP has proven to be an effective model for delivering a patient-centered Medical Home for children with special health-care needs, something that will be increasingly important as we implement health reform.

Female9: If it were not for the parent consultants, I honestly do not think I would have gotten through this experience. My kids would not be doing as well as they are.

[END OF VIDEO]

Female10: Just as Deb comes up, I just want you to know that, I mean I think this is a great video that everyone is welcome to use. If you go to the Catalyst Center, so it's CatalystCRT.org, you can download it. And you know, you really use it as an example of what you can do in your state.

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Female11: I also have some data sheets up here that talk a little bit about the evaluation that we had and you know, sometimes to get things to happen within your own state, like sometimes you need data, sometimes you need stories and other times, you know, it's good to have some of the results that might, you know, happen from what it is that you're working on. So we have a bunch of materials and, you know, trying to help other states as well with some of their ...

Female12: Did it got to sleep? Sometimes the...

DEB GARNELL: Okay, so we the only other things I was going to talk about was just the evaluation that we conducted to do... to find out the different levels of care. So what we did was we took all of the utilization data from one of the health plans that we were working with, the Neighborhood Health Plan, and we looked at kids within the P-PEP program and we compared them to before they entered into P-PEP and then we compared them to their services and their utilization after they had been in the program and we used a control group. We used a control group with the program as well so that we can compare those utilization.

And what we've found is that the kids in P-PEP did use less of the emergency room and they... but they used more out patient services and pharmacy and they used less of the emergency and in patient services. And we also found that when they did

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go inpatient, they were there for a shorter period of time than the kids in the control group.

So there's a lot of you know, interesting things that you can glean from the data and some of the results. One of the things that we know about, services in our state, is that when a child is being either kicked out of school or kicked out of childcare and is having you know, lots of episodes and lots of concerns, behavioral especially, families will go to the emergency and sit there until they get their needs met or they'll go for the child's asthma is out of control or you know, that's a preemie that has come home without a proper plan being in place within the home that they'll be going, you know, directly to the emergency room and to the hospitals in order to get the services and the needs that they... to get their needs met.

So we were seeing a lot of that and we were able to control and to handle a lot of that through enhancing the Medical Home, through families going through more regular appointments. We had heard from a few physicians of their frustration with some families and we hate the word non-compliant, but that's how they would term them when they would come to and say that, you know, I sent this family to the cardiologist when the child was two months old and now the child is a year old and now it needs the surgery because they didn't follow through with that plan and you know, it was a big issue. And we have a parent consultant working with that practice. And you know, he talks about one of our best advocates of the project and

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talks about how he has 100% compliance because most of his families are Spanish-speaking. The parent consultant will say, okay, the person on the second floor speaks Spanish, when you go there, check in with her, her name is this.... Goes through the whole plan about what is the process when you get there, you know, these are some things that you're gonna need. And will really help make the families make that connection and you know, the care is more coordinated, even when we work with nurses and social workers within the practices, that our data is different than their as well. So we follow through with the appointments and follow through with some of the procedures that the medical folks are suggesting is more enhanced when it's a peer-to-peer approach as opposed to another professional kind of coming in and telling the family something to do.

So here is some of our, you know, cost savings and we talk about these things with the insurers quite often. And... oh, I think you were going to ask those, right?

So, we have... so we tried to with out project as well, one of the things that Linda had encouraged us to do was to see how we could provide some technical assistance to other states and to really you know, help put a toolkit together so we feel like so indebted to the D70 Grant for really helping expand this model and to really take it to scale. So we have, you know, prepared some materials on our website and **** and we've actually provided some technical assistance to Nebraska around, you

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know, how to set some things in motion and so we have plans to do a couple of more.

And so anyway, we are open to that and we really want to see, you know, the model and looking at sustainability too. And I think the more we can collectively talk about how pediatric Medical Homes can be enhanced, that it will be better for all of us to really keep moving in this direction.

LYNDA HONBERG:

Thank you. So, we want to hear from you... let me just, before we get started, just because everyone keeps saying D70, and I kind of laugh about it, where did D70 come from. So for those of you who are grantees and those who are not, we have this system called the Electronic Handbook and every grant program funded by, actually by HRSA, is assigned a code. And it just so happens that this grant program is assigned the D70 code. And it's you know, we kind of laugh about it because we've... we've changed the name as things have progressed and really have been working on improving the infrastructure and the reason for that is because these are just three-year grants. For the most part, most of the grantees do as for an extension and do get four years. But at the end of the day, once the grand funding ends, it really has to be sustained through Title V, but also in partnership with the families in which is why, you know, families are so critical because I think we know, perhaps, government workers may come or go or be furloughed, but families, we're always here and we're not going

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anywhere. And our kids are always here. And so those family partnerships are so important.

So, we'd like to hear from you, either questions or just thoughts about what's going on in your state and, I know we've got a couple of current grantees or past grantees in the room as well. So, we have an opportunity to have a good discussion, so let's hear from you.

Question: Josie, could you talk about your process and how you created a relationship within Title V? I notice as you were going through the list of those partners that you mentioned **** very ****?

JOSIE THOMAS: I will. Initially... yeah. It was by dribbles and drabbles. When I first came to Parent's Place many years ago, you know, I immediately... because Parent's Place was just the PTI, it was doing any health work. But in my previous life I had done health work, as Cathy knows. I was at the Institute for Family-Centered Care before I came to Parent's Place, and before that, I was at the Association for the Care of Children's Health. Now, that doesn't exist anymore, but that's where the ACCH Parent Network started, where some of this work started for many of us who are really old; ****, Polly and Betsy and Barbara Popper and many of the others.

So I had, you know, I had come with this health piece and I initially went to the Title V folks and asked for a meeting and I said, do you know about the Parent's Place? Have you ever

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worked with the Parent's Place? And they were very hesitant. So but what had happened that year is that there was the redesign, it was you know, over 89 happened that told us they had to change how they do things, and this was several years later and they still hadn't done anything, but they had had a full evaluation of their system.

And fortunately, it was done by people who have a true belief in what they do. Holly Grace and Henry **** for those of you who may know them who are from Hopkins has said, "The one thing you need to do is develop a relationship with a parent organization." So that... it was just serendipity that those things happened.

And little by little, so our initial bit of funding from them was \$25,000 to do one little thing. We did it and then you know the cast of characters change year after year, which has been something we've dealt...we've had really quite a few struggles with. But over time, that grew. They reorganized and the Director of the Title V with Special Healthcare Needs Program was very focused on genetics and not on broadly kids with special healthcare needs, but she brought in an Associate Medical Director who was more focused on that. And it was very difficult for them.

But that's where we, it was kind of like, we were kind of bonding together to try to make things happen because, frankly, nothing happened. I mean, there was no work being

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done around transition, no work being done around Medical Home, no work being done on any of the core outcomes. So frankly, some of the things that we were doing, because prior to this, we had a healthcare financing grant, one of the SPRNS Grants that we were doing that work.

And every time that something, we tried... something would be tried, it would be stopped. So as I said, frankly for us that everybody left was a really good thing. You know, we made ourselves indispensable. They had work that had to get done, they had block grants coming up, they had reports to do, there was nobody to do them. We were there. So, we were very present and very much in their backyard and very willing to do it.

And one of the things that I truly believe in is not to burn bridges and not to... not to attack people and to work as collaboratively as I possibly can, no matter what I think, so that even though they weren't doing what they were supposed to be doing, I worked very hard not to attack them and to keep it to myself.

As a matter of fact, one of... our new Director, who is here, Acting Director, Donna Harris, you may have seen her around said to me yesterday, we were at dinner. She said, "How did you stand it for so many years? How could you tolerate it?" Well, it was really disheartening because I had been working in the arena for many, many years and I would see other states moving forward and getting funded and doing really

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innovative things, and here we would be. The best thing is that these people left. And the best thing was that the director was asked to leave.

Question: [Inaudible].

JOSIE THOMAS: Yeah, yeah. Yeah, and be willing to do the little **** work and not getting paid for it and being present and just not letting go. So, but we're in a new era. Very exciting.

But I mean, you know, there is sometimes when there is a situation where perhaps Title V is there. I mean if you're a family and you really want to push Title V. I mean, I think we have a lot of examples and certainly you're got a great relationship. Maybe you want to talk about the good relationship you have with your F2F. Because I don't want, you know, there is... one think I've learned with these grants, and the block grant in general is, every state is won different. And the partners do change and shift. It's rarely static. Which is why, in terms of these grants, we do have to be flexible. And what Josie was saying is I recognized that that people may submit a work plan, but we work in a very dynamic environment in that things change, but the constant is the families.

JOSIE THOMAS: So, when I was brought in to the Special Needs Office at the Health Department, the Review Committee or the Interview Committee actually had a family member on it. And that, from

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the legacy of Dr. Hollandshead, who you now, just believe strongly about parents being involved of all levels of decisions and being involved, so anyway, even in his retirement, it still carries that same message.

So that has, but it is also, I think from myself though when I meet with other states and when I talk to other Special Needs Directors that, it's very difficult for a Special Needs Director to ensure that systems in your state are coordinated and that they are meeting the needs of families because we don't do... at least in Rhode Island and in many of the other states now are transitioning, we don't do direct... you know, we don't do direct services. We don't have case loads, we don't... in direct contact with families. And so it's one thing to get the National Survey data and just say, okay, you know, 750 families said this about your services in your state, but it's really you know, what is between the lines there.

And you know, we... I kept hearing before I was the Special Needs Director that service in Rhode Island were so coordinated, they were this, they were that, high insurance, you know, we had all these areas that we were at the top of the top, but Massachusetts mostly really getting up their numbers, ones and twos, you know on all these different indicators, but we knew that there was so many, you now, families with special... raising kids with special needs that were breaking up and that they were, you now, just all of these other issues around finances and around you know, their struggles with

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their lives. And yes, they got the services that they needed, but it took them three or four years to get there and they've gone to multiple schools and through multiple towns and you know, all these different systems.

So, we were saying, "No, services aren't as coordinated as you know, they appear to be." So sometimes the families would be frustrated with the data that they would hear back and you know, say that, "No, this is not as good as you now, you're reporting." And so we definitely, and, you know, also from a practicality, I think that you had mentioned to that it's hard for the state government to spend money to get services out there and to be more creative. The best thing we did was to work with our parent organization because they have less of the stringency that, you know, we have as state government.

So we have in the health department now, we have about 45 parent peer resource specialists that we employ and it's all through the **** Parent Information Network. And I have, it's just myself and one other half-time staff that's our Special Needs Office. And so, whenever we get money, whenever we have things that are happening, you know, we put the money out into the community and into these resources. And so it's not just another no state staff that can write into the contract, you must the family-centered, it's actually people that are out in the community center in ensuring family-centered care.

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So, you know I've had that conversation with several Special Needs Directors and others in states like, you know how are you really hearing what's happening from your families? So I consider those 45 folks, you know I consider them my staff and giving us feedback and really putting into the process of how to make systems change and, you know, we have an area of legislation or whenever there is little things that are happening, we can deploy folks to really get out there and to make a difference. So there definitely is a good working relationship as well between Title V and parent organizations.

JOSIE THOMAS: Well, I'm looking in the audience, I know I have a couple of grantees and Michelle, do you want to come up and just, if you don't that's fine, I don't want to put you on the spot, but certainly Pennsylvania has done a lot around partnering with their families.

Michelle: Sure, I was just gonna... ****. I was just thinking of something that Josie said, from Maryland. We consider ourselves very fortunate because I was, one thing I was thinking about what she said about how easy it was for how difficult it was for states to actually work through their bureaucratic organizations and actually get money out to grantees were to actually get the dollars out, we had a very unfortunate set of circumstances once we actually got our D70 grant and we actually had to call Linda and say, "we have a little change that we need to discuss with you."

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We're very fortunate I think in Pennsylvania and once we wrote our D70 grant to be working with our Family to Family Center agency, Liz Haley, maybe some of you know is our Family to Family information grantee. She was one of the partners on the grant as well as Renee Turchy, who is our Medical Home grantee, but anyway, we had to reorganize things and so we actually worked with those two women and had to reorganize the grant and we actually had to redo things a little bit, but we had to restructure what we did and research all things a little bit, but in the end it was our Family to Family partnerships that really saved us. But we worked with them and restructured things and really now, it was the Medical Home piece in the family piece that brought us together.

We have really strong partnerships, what we call Parent Youth Professional Forums that have worked very well for this **** grant and they are Parent Youth Professional Forums that we have, that we work with through the **** grant that have brought us some really good feedback across our state and I'm hoping that Linda is actually going to join us here in a couple of months for our second consortium for this grant, the parents, and the youth and the professionals are bringing together some good information back to the state and they are challenging us because they have brought some really good information back to us and we're now, as the bureau, going to work on their recommendations and actually through this grant are going to make us be challenged and take the next step forward.

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But in the end, we actually had to work through the grant and we thought we would be challenged and actually have to get the money back out through the families, but we had to turn around the cycle and we had to scurry around, but we were actually able to get the money out. But I commend what you did because it's hard losing staff, but we did it, so it was interesting.

JOSIE THOMAS: We're in a better place.

Michelle: I—I think you are, and I commend you for that. It's good. Thank you

JOSIE THOMAS: And John, you asked about the relationship with Title V, it's really right now, it's fabulous. I was even on the Selection Committee for the new people. So you know, there are people that we were able to develop relationships with even before this happened. So, that was good.

LYNDA HONBERG:

So I don't know, Michelle or Ron, if you want to come up. I don't want to put you on the spot, but... Okay. And you did a presentation earlier, did you now? Amy did. So, if you look in the program actually, there were a number of presentations by the either Title V or the parent organization that's been funded under this initiative, including Boys Town, in Nebraska. Which is one of those unusual grantees, remember I talked about the

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majority are Title V, but Boys Town is, I think, one of our more unique grantees.

Michelle Mertz: That's, Nebraska is usually quite unique, so I'm glad we were able to live up to that. Yes, I'm Michelle Mertz, I'm with the Boys Town Institute for Child Health Improvement and our Title V department in the state was not in a place that they could facilitate the D70 grants. So we were happy to work with them to facilitate it in Nebraska.

And when we started out with our grant, it was pretty straightforward, we did a learning collaborative where we brought together pediatric practices, one of the big issues in Nebraska is, of course, rural, since 70% of our population is within about 1% of the landmass. So it is a big issue.

One of the things that became clear right away in the learning collaborative site was that all of the pediatric practices were struggling with care coordination; how to make it happen. So we took that on as our goal, we're going to find a way to help these practices make this happen and make their care more family-centered. And it just so happens that we came to AmCHP last year and heard Rhode Island's presentation and this big light bulb came on over our heads and said, we have got to do this. This is exactly what is going to make things happen in the state of Nebraska.

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So again, thanks to the flexibility of Linda, we were able to do our own pilot, it was very small. We hired three parent partners that we put out into the community. We visited Rhode Island to learn from those who were doing it was. We had to tweak the model a little bit to make it work in our state, but one of the things that we learned really quickly is, share your story, share what you're doing with everyone, whether you think they can be a partner in helping or not because and sharing our story with some people in the states who are on the education side, and working in medical, they have my fault moment and they said, oh my gosh, this is exactly what's missing from our program. It was our Early Development Network Group, and what they were hearing from their customers was that there was not good coordination amongst these referrals.

So the pediatricians were making the referrals to EDN, the pediatricians were angry because they weren't getting follow-up and EDN thought they were getting the right information from the pediatricians, and then the patients were just kind of left hanging and nobody really knew what was going on with what these patients were getting. So they gave us further funding to higher for more pediatric parent consultants who we have since put into the practices and it has been an overwhelming success.

So this model that we thought was going to be medical and was going to be driven by the state is actually being driven a lot, at

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this point, through education and hopefully with that funding will be able to use it to sustain our model both on the medical side and on the education side.

LYNDA HONBERG:

That's great. Thank you. Other questions or thoughts in terms of how to involve families? Other promising practices out there?

Well I think one thing we're hearing is also the flexibility, so. Well if this was eight... unfortunately this is being videoed, so I can't...

JOSIE THOMAS: well I was kind of worried about some of the things I said to, so I was hoping this going to be **** on the website.

LYNDA HONBERG:

Ron, do you want to just talk about what you did in Massachusetts. I don't want to put you on the spot, but I want to give you the opportunity. We have a few minutes because... and maybe, you know just talk about, this is the other side that when there isn't the ability to sustain something.

Ron ****: Okay. Ron ****, I'm the Title V Director in Massachusetts, I'm also serving as the Special Health Care Needs Director, and I'm also the Part C Coordinator. So here's the have for today. It's not all by designer choice, it's more that you take on something... someone says if there is not a crisis going on then you just keep doing it. But I guess I would say that we never described our

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grant this way to Linda, but I always called it the "kitchen sink" but it was a braided kitchen sink. And we sort of talked about it that if someone read it, if you weren't willing to look at how you braided a variety of needs that existed in the state to make up a whole or a tapestry, then you would probably say, well this seems to be very disparate kinds of things that you're sort of trying to address.

But I think in terms of things related to sustainability, I guess I would say couple of things about two items in our experience. One was our own consortium, which actually had been fairly long-standing. It was... really had been guided by New England's **** that many of you are probably quite aware of. And I think the challenge was that there was both the desire to influence policy, it was a desire on some people's part, I think not to have sort of an action faction, if you will, which I was part of the action faction crew that said can't sort of just do something and then stand on the sidelines about what you need to do if you need to do it. You have to be willing to sort of step out of that role a bit. And I don't think that in and of itself is what made it problematic because we had any number of partners that were on the consortium, but at the end of the day, and I guess he has of his day being about three years ago, which is incredibly hard to find money, even within state dollars or insurer dollars who were good colleagues of ours, but we were just not able to sustain that.

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And the other is that, I think in one of the first life that you put up the family professional partnership that we embedded families and any variety of care settings including health plans, community health centers, hospitals and again, it's a hard thing unless there's sort of free dollars that you can find pretty easily. Either that or you have to define something that you're already funding and if you feel like those are good things that you're funding then you just have a conundrum you're in and generally speaking I think the things that have been more long-standing stay and the newer ideas you hope you'll get another shot.

LYNDA HONBERG:

we've got some people in the back of the room, do you have any thoughts or in terms of... what state are you from? Texas, okay so Texas is one of the states that we have not funded yet. Again our...

Female: I need a **** ...

LYNDA HONBERG:

Oh good, so hopefully this will help you. I mean, like I said, the Bureau's been committed to making sure that every state really has the pieces in place and wants to have this grant does that successfully funded. Because we do think it's critical to the mission of families into Title V. And we do, and I don't want to and I may somewhat of a difficult note because we do know, these are difficult to sustain and especially in these difficult times. But I think if you look to your families and you

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look to your other partners, that hopefully certain aspects will be sustained. And I think Ron, that the ability to partner with each other has been sustained in Massachusetts, so I don't... I think people need to walk away from that that we don't expect every part of a project to continue, but that partnership and really seeing families as agents of change in recognizing that has been critical.

So, I thank you for staying, I know it's, looking out the window the sun was shining. Some of you from cold weather climates have been, there is no snow here. But feel free to come up and I'm always available for questions. We've got lots of technical assistance that's available, **** national centers or are current grantees and as you can see, we really do talk to each other and try to spread good ideas among each other. So thank you for your participation.