

**2011 AMCHP and Family Voices National Conference: The Role of Family Organizations in Enhancing Performance on the Core Outcomes for CYSHCN**

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Female: So Josie, we have it.

JOSIE THOMAS: Yes, we do. I'm introducing people.

Female: Okay, great. You're going to have to read that because now you're the moderator.

JOSIE THOMAS: Okay, so welcome everybody. My name is Josie Thomas. I'm the director of the Parent's Place of Maryland which is the Family-to-Family Health Information Center for the state of Maryland. We also serve as the Parent Training and Information Center. We're the Family Voices state affiliated organization and we also have the State Implementation Grant. I feel like I'm right in your face Mike because sitting down and my standing we're about the same eye level.

Diana Autin is the director of SPAN of New Jersey.

DIANA AUTIN: Co-director.

JOSIE THOMAS: Co-director, she is at the podium trying to get our PowerPoint on up and Diana will tell you more about herself when it's her turn.

This presentation is entitled The Role of Family Organizations in Enhancing Performance on the Core Outcomes for Children and Youth with Special Healthcare needs. It is session ID F7, which is a workshop, AMCHP, Family Voices shared session. This session is accredited for continuing education. Immediately following the conference a link to the CDC training and continuing education

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online system will be posted on the AMCHP website. In order to receive continuing education you must complete the online CDC continuing education evaluation form by Monday, March 12<sup>th</sup>, 2011. Be sure to keep track of the sessions you attend throughout the conference as you will be required to enter this in the online system. A tracking sheet is provided in your conference bag. Further CE Information can be found on page 10 of your program. A conference evaluation survey will be posted online immediately following the conference. A link to the survey will be mailed to all attendees. AMCHP will use your feedback to help plan future conferences. Your input is very important and greatly appreciated. Finally, please turn cell phones to silent mode.

Now I've already introduced the presenter, so I'm going to not read this last part. Thank you very much for coming today. We have a very small group. If we can just very quickly go around the room and tell us who you are, the state you're from and your role because I think that's going to be important. Let's start with you Donna.

Donna Harris: My name is Donna Harris and I'm the acting director for the Office for Genetics in children's special healthcare needs in the state of Maryland.

Dennis: I'm Dennis Quo [ph]. I'm on the pediatrics faculty, University of Arkansas. I work at Arkansas Children's Hospital and I'm also involved as a consultant \*\*\*\* for the \*\*\*\* Family-to-Family in Arkansas.

JOSIE THOMAS: Michael.

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Michael Warren: Michael Warren. I'm a general pediatrician and director for Title 5 MCH in Tennessee.

Female: My name is \*\*\*\*. I work in Puerto Rico.

JOSIE THOMAS: In where?

Female: Puerto Rico.

JOSIE THOMAS: Puerto Rico, okay. Jinness [ph].

Jinness Ross: I'm Jinness Ross. I'm \*\*\*\* Center in Tennessee in Memphis. I'm \*\*\*\*.

JOSIE THOMAS: Great, Roger.

Roger: I'm Roger \*\*\*\*, director of the Parent Center in \*\*\*\* which is also \*\*\*\*.

JOSIE THOMAS: Brada [ph].

Brada Estrada: I'm Brada Estrada, associate director for Workforce and Leadership Development at AMCHP.

Female: I'm \*\*\*\* Clark. I'm with Vision Special Interest which is the CFHCM program in Illinois.

JOSIE THOMAS: Okay, good, welcome.

Marilyn: I'm Marilyn \*\*\*\* Family Network \*\*\*\* from the state of Florida. \*\*\*\*.

JOSIE THOMAS: Great, I'm glad you're here.

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Janet: Hi, I'm Janet \*\*\*\*\*. I'm with \*\*\*\*\* and Voices. It's a parent advocacy support organization for families who have children who have deaf or hard of hearing and \*\*\*\*\*.

JOSIE THOMAS: Great, thank you for coming. I'm the parent of a deaf child, so not so child anymore. He just turned 30 this year.

So we're going to talk a little bit about the role of family organizations in implementing the six core outcomes. There is a lot of distractions. And we're going to focus on two states and the reason we're focusing on these two states is we were two of the initially funded states around the state implementation grants. Maternal and Child Health Bureau has what they call these D70 grants that go to groups and states to implement the six core outcomes and Nevada and Maryland were the first two to get funded. Typically it's the Title 5 program or some other group, but the Family-to-Family got funded in that state and then the following year Diana in New Jersey was funded and so we've had quite an impact on our states for a variety of reasons and more and more as you know state Title 5 leaders and parents are being asked to work together as we implement the six core outcomes and the states are implementing them in a variety of different ways and today we're going to share some of the things that we've been doing hopefully to give you some ideas and some strategies for going back to your states and doing some of this.

We're taking the lead in our states because we're the D70 grantees and we have the money to do it and are able parcel out some funds

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to make it happen, but working together in these ways is different for a lot of us and it means letting go of some old habits maybe, old ways of doing things and looking at partners in different ways and for some of us working with state—as parents working for the state government for the first time we kind of have to do a little dance to figure out those relationships and it enriches the relationship tremendously because different partners can do different things.

So the next slide. There are tons of barriers—I don't quite know where the stand—to implementing the six core outcomes, not so much to the partnership. As is happening in every state across the country there is huge budget cuts. The staffing positions are cut and hiring freezes are impacting kid's health. It's impacting what the state agencies can do. The Title 5 programs are really impacted. I know specifically in Maryland it has been a huge issue. In some of our state programs waiting lists are growing, not so much because—some of it because of money, direct money to pay for services, but some of it is because the positions are gone and there is nobody to do the work. For example, our Division of Rehabilitation Services this year the waiting list grew by 600 and it wasn't that they didn't have the funds to provide services. It's that they didn't have the staff to do the work. That is an issue.

As we know, the system is very complex. We're asking Title 5 agencies to implement six core outcomes statewide in very complicated systems with not a whole lot of money.

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DIANA AUTIN: And where they don't control all the systems that have to be impacted in order to make the six core outcomes a reality.

JOSIE THOMAS: And the very last point, as you know, there is not enough integration between programs. We've got these silo funding streams and even in some places where maternal and child health doesn't talk to children with special healthcare needs. God forbid they should work together or shared planning or sharing of resources and so those are the contextual barriers that state agencies are facing and trying to make the six core outcomes a reality. I'm seeing nodding. Is that how your experience is? Yeah.

DIANA AUTIN: And one of the things that happened in both Maryland and New Jersey that resulted in the parent organization being the organization that applied for the D70 grants and in our case also the next year, the integrated systems for children with autism spectrum disorders and other developmental disabilities, is because our state agencies knew that they didn't have the sufficient infrastructure, that there were hiring freezes, that even if they got the money they wouldn't be able to hire the people to do the work and they also felt that because we were parent organizations that we could bring that extra push and advocacy push to make the work around the six core outcomes a reality and so for both of us it was really our state agencies that encouraged us to be the agencies that would apply to get the D70 funds.

JOSIE THOMAS: Right. In addition in our state and I don't know if it's the same with yours, getting contracts out is really difficult. Donna could certainly speak to that, so that we had written a number of sub-

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awards to different groups like the AAP Chapter and other places and we knew that if the state got the grant there was no way that that would be an easy process to get it on out to the different folks, so it was easier for us to be the lead agency and because we can just cut a check. We're a nonprofit and that made the process much easier.

DIANA AUTIN: But of course you know the level of trust that had to exist between the state agency and the parent organization in order for the state agency to say, to make that leap of faith that it should be the parent organization that would be the lead agency.

JOSIE THOMAS: So this is really hard to see. I'm so sorry. I'll read some of it to you because it's pretty funny. Fifty reasons not to change, we're talking about really dramatic change when you're letting go of control and asking a family organization here go handle this: "It's too expensive. I'm not sure my boss would like it. It's too ambitious. We'll catch flack for that. No is me problema. It will take too long. What's in it for me? They won't fund it. It's too radical. There it too much red tape."

DIANA AUTIN: We don't have consensus on it yet.

JOSIE THOMAS: "It's just a fad. Here is another one, "No se puede." "Can't do it." "I'm all for it." You've all heard all of these over and over and over again when you try to implement change. Sometimes change is going to happen whether you go for it or not and we're going to talk about these kind of changes in a little bit. I think this one is your Diana or you want me to do the next one.

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DIANA AUTIN: So I'm going to ask is it okay if I talk or do you need to have the person who has the-?

Male: Yeah, I got it.

DIANA AUTIN: You're okay. So why family organizations? Well of course we're a little bit prejudice because we are family organizations, but we think that family organizations are important because we are indispensable partners in improving the quality of systems and access to systems. Family organizations bring multiple perspectives and diverse strengths and talents that can help achieve the goals. We are the ones who can provide a reality check about what is really happening on the ground because we're talking to families and community-based organizations every day. We talk to families every day and because we talk to families every day we can tell you it may be working here, but it's not working there and we are easily able to reach families and others to provide information, resources and to gain knowledge. That is what we do as a family organization and of course last, but not least, it's critical for the advocacy component and for the accountability component, so families, as family organizations we can advocate in ways that sometimes Title 5 can't advocate or feels they can't advocate and we have the constituency to hold systems accountable because our constituency are the families who are trying to use these systems and trying to achieve the six core outcomes for their children.

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So what are some family organization roles and I think one of the things our American Academy of Pediatrics Chapter says all the time is, “You know what?” “When we talk to doctors they have no idea what a family organization can do.” They think of a family organization in such an old-fashioned way, as a little group of people who can give a family perspective. They have no idea about the breadth and range of services that family organizations can provide and the knowledge, so we’ve got knowledge. We can provide support to state agencies and others in implementing change. We can provide perspective, a wide perspective because we’re working with families from all different backgrounds and professionals too. At SPAN about a third of the people who come to our professional development are professionals, so we’re touching a lot of professionals as well. Family organizations can help build relationships. We get a lot—we don’t get very much money and so the only way we can do our work is by having strong relationships with other community-based agencies, with other providers, with families on the ground. With volunteers, parent volunteers. Family organizations can communicate with honesty. We can say this is working, this isn’t working, this is working for some, it’s not working for others. We can reach out and engage families. Core outcome number one, families are engaged at all levels and satisfied with services and family organizations that is the heart of what we’re about, so we can really help engage families and especially families from underserved communities. More and more family organizations, whether we’re funded by the Department of Health and Human Services of the Department of Education we’re being required to

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demonstrate that we are reaching and supporting, effectively, families from underserved communities.

We can build parent leadership capacity and that is the number one requirement for sustainability. Parent leadership in communities is the number one requirement for sustainability because when you have informed, educated, effective parents then you're going to have people who are demanding that the changes that have been made will be sustained and also family organizations can encourage change because we are the ones that are hearing from families every day. We're the ones who know that change has to happen in order to meet the needs of children and families and then of course family organizations are critical in monitoring implementation to make sure that improvements are taking place that that they're having the impact that we want. It's not like an exact science that if we do this it's going to have the outcome that we want. We've got the contact to the families on the ground to let us know did those changes that we make actually work in the way that we wanted them to work.

And you know Josie and I like you to ask questions along the way. We're not those people who say save your questions until the end, so if you have questions or comments or thoughts along the way we want you to say them please.

JOSIE THOMAS: Okay, we already did this.

DIANA AUTIN: Yes, okay, we have two examples.

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JOSIE THOMAS: Okay, this is us and the Community of Care Maryland Consortium for Children with Special Healthcare Needs is what we call the grant, but also the activity that we're doing that I really want to talk to you about. You can go to the next one.

When we applied these were our partners. You can see we weren't by ourselves. We have the Title 5 Children with Special Healthcare Needs Program, Johns Hopkins School of Public Health, who is doing the evaluation, the Maryland chapter of the AP, Johns Hopkins School of Medicine and Maryland Healthy Kids. I spelled that wrong, Healthy Kids, which is the EPSDT program in Maryland and I'm going to explain to you why we ended up with those partners because it's not how we started, but it kind of evolved to that.

These were our goals when we started is to implement the leadership and infrastructure to achieve and sustain integrated community-based system of services, to improve developmental screening, to improve access to medical home and to improve transition, four issues that were just not happening in Maryland. For more than 20 years Maryland had been functioning—the Maryland Title 5 Children with Special Healthcare Needs program—Donna, I'm just going to say it, under leadership that was antiquated and very interested in doing clinics and those kinds of things, so the process of change that Title 5 Children with Special Healthcare Needs is supposed to have happen since October '89 that mandated the changes just had not happened, had not occurred and things got so bad at our Title 5 program, who were our partners in this grant that two months after we were

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funded everybody was gone. They were contributing 1.1 FTE to this project and we were left thinking what are we going to do.

Part of it was relationships that were not working. The directorship of the program was not—it wasn't working well, so we were left with this huge mess of trying to figure out what to do and frankly, it ended up being a huge opportunity, a huge opportunity with this void in leadership to do things differently and to take charge of it and have it happen, so I'm going to explain to you a few of the things that happened. We had to restructure some of our goals in this grant. The federal government was—HRSA was very supportive. The Consortium is phenomenal. We started off with a two-day summit where we invited everybody in the state to come and play, everybody from education to mental health, to Medicaid, MCOs, parents, everybody we could think of and we built a consortium on that and it's a broad alliance of stakeholders and in the void that happened with Title 5 we just went ahead and moved forward. We went ahead and built relationships in communities. We went ahead and worked with who was there to do strategic planning and just presented it in that way.

I'm trying to think of—you want to go to the next one? So here is what the COC has been doing. We have about 35 to 55 members that come to these quarterly meetings. That is s pretty phenomenal. Every time we have a meeting and all these people show up we say, "Why are they here?" We can't quite figure out why they come and we keep hearing, "This is really important for us." I think for the first time in our state we have a group that is focusing on children with special healthcare needs and the whole

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community is invited to participate and we make sure that every time we come together we do something. We don't just talk. We do something. We really work on it and last year that we had the Title 5 needs assessment to get done it was just prime. It was great.

So we've done a ton of educating of the members, the stakeholders and everybody. Title 5 in Maryland is a big secret and folks who started attending this came because they knew us and they liked us and we have a good reputation in the state and they thought they were going to get lunch for the day, but they continued to come because this program is evolving and it was a well kept secret. You know that Donna. Nobody knew what this program does.

Donna Harris: I worked in the program.

JOSIE THOMAS: So one of the things we did is we provided mini grants to folks in the communities who were working on implementing six core outcomes and every year we have funded four to six little mini grants and they've gone to really interesting things. For example, the AAP Committee on Children with Mental Health Issues, Ken Tolomen [ph], is working with a group and working with pediatricians and mental health providers together to insure that there is a connection for pediatricians and support when they're serving kids with mental health issues and we're the conduit for that. Can you imagine? I mean really, family organizations. What is happening is that we're working in a couple pilot projects with them, with their mini grant to—with some—federally qualified community health centers in rural areas of the state where there are

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no mental health providers and so we're the link. They do the intake. It gets sent to us. We connect them with some of the mental health providers in the community. We set up a telemedicine with them and we provide services to the family, so it's really cool. The mini grant is allowing that to happen, to test it and to try it out.

DIANA AUTIN: Can you imagine organizations for the small amount of money that these mini grants are going through a process that would usually be required by a state contracting process to get that little bit of money? It just wouldn't be worth the effort, but a contracting process that's done by a nonprofit can be a lot faster, a lot shorter and a lot easier and it's just the little bit of money that's needed to make it happen without having to go through the hoops that as a state organization you have to put in place.

JOSIE THOMAS: And what it does is it gives people an opportunity to try things out to see if they'll work. For example, we have—we funded a mini grant to the Sickle Cell Association of Maryland to do some outreach and to develop some materials, but what we're also doing as a condition of the award is they have to participate in our COC, so we're trying to loop it all up and we're offering them Hopkins School of Public Health evaluations to help them build in quality measures and evaluation into their little mini proposal, so it gives them a chance to build some evaluation skills, so it has been very exciting.

The needs assessment this year specifically for children with special healthcare needs would not have happened if it hadn't been

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for this group and for our partnership. We were left with a grad student, mind you, a very smart, brilliant grad student who did the needs assessment for children with special healthcare needs, but it couldn't have happened without the family organization and without our COC.

We conducted a statewide survey and had almost 1,000 responses from families, so we're pretty excited about that. That is pretty big and we're working as a group to influence policy and legislation. A lot of our members can't do that, but we can, so we sit and talk about it and figure out what is it that needs to get talked about and we're the ones that go to the front of the line and go ahead and do it, not with federal dollars of course.

The other thing that we've seen happening over the course of two years is that it's an incubator for family leadership. We work really hard to get families. They're particularly families who don't typically come to such things. We provide them transportation and childcare stipend and set them up with a mentor parent so that they can come and participate at this policy level. We're done with the COC.

We've got this persistent focus on key systems and central issues and now as our new leadership is in place, thank goodness, we continue to work on that partnership in that this COC then really becomes the advisors for the program to help keep them focused and on track and watching what they're doing. Right Donna?

Donna Harris: Yes, absolutely.

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JOSIE THOMAS: Okay, go ahead. We had four objectives. We really whittled them down to two. I don't know those of you who attended an earlier session today on developmental screening with Tracy King. If you didn't we have a phenomenal statewide focus on developmental screening. Through the AAP we subcontracted with them to do regional training for pediatricians around developmental screening. The Maryland Children with Special Healthcare Needs Survey our numbers were really low and so there wasn't a lot of developmental screening going on. It was primarily surveillance and so through—we started with the ABCD Workgroup and because of that ABCD Workgroup around developmental screening we were able to pass legislation that raised the reimbursement rate for developmental screening and added a 30 month screen. Also were able to identify the six screening tools that would be approved by Medicaid and recommend two so that pediatric practices in order to be reimbursed by Medicaid had to be using those practices.

So with the AAP we have—we built a training program and conducted it regionally. Over 450 pediatric practices have been trained and each of those trainings were conducted by a physician and a parent and infants and toddlers, our early intervention program and the reason we did that is because once those kids are screened and if something comes up we want the pediatricians to know who to refer the families to. One of the things we learned in doing focus groups is that pediatricians in our state didn't know what the resources were and where to refer families, so that has been really phenomenal. Then the next thing.

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Then in working with Tracy King, a pediatrician at Johns Hopkins School of Medicine we worked on intensive support for selected pediatric practices in Baltimore City and working through Reach Out and Read Program and a consultant that works with us we do onsite technical assistance because what is happening is we can provide the training, but folks need the support to figure out where in their office procedures are they going to put in that pediatric screening. Where is it going to happen? Who handles the forms? Where do they get stored, that kind of thing? And back up one more because we're also doing reach—no, go ahead. We're doing Outreach to Family Practice sites, so we've moved beyond pediatricians. Now we're looking at family practitioners.

Next one. Keep going.

DIANA AUTIN: Now the Reaching out of Families.

JOSIE THOMAS: Yes, there we go.

Male: \*\*\*\*. I have a quick question about the—back one slide.

JOSIE THOMAS: Yeah, the intensive support.

Male: Yeah, \*\*\*\* intensive support, I mean did you do regular visits to them, just schedules visits to practices or did just wait for them to call you or how did that work?

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JOSIE THOMAS: No, we reached out to them and we focused primarily in three sites at first, a federally qualified health center, a hospital based primary care setting and then a community based setting, but what happened is that they were parts of other groups, so as the other groups heard and the discussions happened it grew and grew and we started off with 3, then it went to 18. Now we're at 30 and it's growing exponentially.

Male: That's nice.

JOSIE THOMAS: And the tie with Reach Out and Read has been really important because Andrea, who was doing Reach Out and Read for Baltimore City Health Department already had the connections, so tying that with the visits to the pediatric settings to help them set up their developmental screening process has been great and she goes at the beginning. She watches what is happening, takes a look at where would it be natural for that screening to happen, at what period in the visit. I really love this stuff. I mean I could talk about it forever, but what we're finding is in some—particularly in Baltimore City we really are going to have to reach out to parents, to families of young children because there is—Tracy's data shows—we've been keeping tons of data—that there is a huge drop off once there is a failed screening and the families are given a referral. There is no follow up and so we're going to try to figure out if we can come around the other side and as family organizations working with some of the families we know in the city to have them reach out to other families to see if we can do some education around what is a screening, what does it look like, what happens when a screening is, so that there isn't that drop off

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and we're going to keep track of that, so this to us is really exciting. We really love it.

So what has happened since then is I said there was a total void last year in Title 5 Children with Special Healthcare Needs and we had Meredith, our grad student who was working on the needs assessment and us and there was nobody to tell us we couldn't do it, so we wrote the priorities for the next five years and they're to sustain the strategic partnerships that we have with this consortium to focus on medical home. Data sharing has been a huge issue with programs and then on focus on transition. We submitted them. Nobody said anything and they were approved, so next five years are going to do what we wanted.

So this is our website and it's just we've had phenomenal success because there wasn't anybody to get in our way frankly and I think frankly, they were grateful to have somebody be doing the work.

So I'm going to turn it over to you.

DIANA AUTIN: Okay, so Josie can you handout the first handout that is right on the edge there?

JOSIE THOMAS: This one?

DIANA AUTIN: Yes. So our work is called Integrated Community Systems of Care for Children and Youth with Special Healthcare Needs and their families in New Jersey. We have some core partners and our core partners are the statewide parent advocacy network, us and we

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house the Parent Training Information Center, Family Voices state affiliate, Family-to-Family Health Information Center, statewide Parent-to-Parent, Federation of Families for Children's Mental Health. We have several transition to adult life projects. We have a CHPR Immigrant Outreach and Enrollment project, so we're really the one stop for families in New Jersey. We work with families with and without children with special healthcare needs, so we have a lot of things under one umbrella at SPAN. We're also working with the Pediatric Council on Research and Education, which is a nonprofit arm of the American Academy of Pediatrics' New Jersey chapter and also with the American Academy New Jersey chapter and then we have three state agencies that are important for children and youth with special healthcare needs. We have our Department of Health and Senior Services, which is our Title 5 program. We have our Department of Children and Families, which is where our Child Behavioral Health Agency is housed and we have the Department of Human Services, which is where Medicaid and SCHP is housed as well as our Division of Developmental Disabilities, which doesn't do a lot with kids, but they have an office—they now have an office on autism, so they—so we have three state agencies that are part of our—what we call our core team and so—and we actually got permission from all of our state agencies to use their logos on all of our materials, so our stationery and our folders and our handouts and all of those things have the logos of the three state agencies as well as SPAN and AAP New Jersey and P Core [ph], so I tell you some of you know what that is like.

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So we also have a leadership team. We started off calling it an advisory committee. This is the Community of Care Consortium that meets four times a year, but now we call it our leadership team and it includes parents, all of our committees are co-chaired by a parent of a child or youth with special healthcare needs and somebody from a state agency or from AAP or another one of our partners, advocacy organizations. All the major disability organizations are part of it. We have our Medicaid health maintenance organizations are part of it. We have hospitals, including our Association of Children's and Teaching Hospitals as well as the New Jersey Hospital Association. We have the Association that represents all of our federally qualified health centers and many others.

We started off with 20 core—20 team members and now we're up to 80 organizations that are part and we generally have anywhere between 50 and 60 people including decision makers, key decision makers who come to our quarterly meetings and with our new integrated systems grant we also have representatives from our six regional clinical enhancement programs for kids with autism and other developmental disabilities and again, it's decision makers from those organizations who come to our meetings, so this was what our initial meetings kind of looked like when we had 20 people and now we have to hold them in three rooms at a library because that's what it takes to hold all the people who come to our quarterly meetings.

I just want to say what is the role of family organizations in the six core outcomes and so I just wanted to share our mission which is

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to empower families and inform and involve professionals and others interested in the healthy development and education of children to enable all children to become fully participating and contributing members of our communities and society and our focus, our foremost commitment is to children with the greatest need due to poverty, disability, discrimination, immigrant status, geographic location, etcetera and our motto, which fits right in there with the core outcome number one is empowered parents, educated, engaged, effective.

One of the things that has been a real strength in having this project housed at SPAN is that we have a longstanding focus on underserved families. We have strong collaborations with organizations like the New Jersey Immigration Policy Network, which is a member of the team, the New Jersey Hispanic Directors Association where all of the organizations that serve children and families who are Latino or Hispanic belong to that organization, they're represented, NAACP, the federally qualified health centers. We have a partnership with the National Center and Cultural Competence as well as the Cultural Competence list serve in New Jersey, a coalition in New Jersey and the resources that we bring to bear like Traducela Ora [ph] and some of—today, this morning we talked about language access requirements that all federal grantees have. We have a great grant from IBM which is access to Traducela Ora [ph], which is a web based Spanish translation program where you can instantaneously see any English language website in Spanish like that and parents who only speak Spanish can write emails in Spanish to doctors and other professionals and they get it in English and it's sent back in English and the parents

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get it in Spanish and there is also a translation feature where parents can send themselves emails with their IEP or prescriptions or whatever and they send it to themselves using this translation program and they receive it in Spanish and it's about 80% effective. It's really high quality and we offer it to anybody who agrees to sign an agreement. Four key points, they won't charge families, etcetera. If you're interested in that see me after because IBM has given us permission to share it with others. It's right on our website. It's a fabulous resource. Did you have a hand? Okay.

And also the language line and we have a very diverse staff and volunteers. We have about 60 staff around the state and about 250 parent volunteers. About 60% of our staff is Latino or South Asian or African-American, etcetera. Our staff speaks nine languages. Not every project has staff that speak nine languages, but we've got the capacity to have cross work on different projects and we have a very diverse group of volunteers as well in part because we do our apparent leadership training for volunteers in multiple languages, so we are able to attract and recruit families from various—who speak various languages, so again we are the one stop for families in New Jersey.

And I really like this. This is actually a quote about medical home, but this is kind of how we see ourselves at SPAN. SPAN is not a place. It's a model of delivering family support that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective, so we really see ourselves as being kind of the community home for families, including

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families of kids with special healthcare needs. So we were so lucky that Josie had already done this when we were getting ready to—when our state Title 5 agency asked us to apply because I reached right out to Josie and we had done some cultural competence work together with underserved families. I said Josie I know you've got this grant and would you share your proposal and she did and so of course we had to revise it based on New Jersey's situation, but it was a wonderful starting point and it really made it a lot easier for us and our purpose of our integrated systems project is to engage stakeholders in activities that are aimed at improving results on all six core outcomes and now that we have the second state implementation grant including children and youth with autism spectrum disorders and other developmental disabilities.

I have to say our second grant builds on our first grant. It's not like we have a whole bunch of separate activities that are all about autism because we were the ones in our state that opposed the autism only insurance legislation and got the legislator to expand it so that it covered more broadly children with disabilities, not just kids with autism, so it enables us to hone in on issues that are particularly important for children and youth with ASD and other DD and their families, but it's building on what we're already doing. It's not segregated. We don't believe in segregation at SPAN.

So what are we doing in terms of families or partners at all levels and satisfied with services? Well one of the things. Our state had long funded us to have part time family resource specialists at 11

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of the 21 county special child health services case management units. We have a great system in New Jersey where every county has a children youth with special healthcare unit to provide case management and care coordination, so we were able, with these funds to hire family resource specialists, so now we have a family resource specialist in every county and now we also have them at the six clinical enhancement programs. That is with the second grant, so we have parents, trained parents who have navigated multiple systems at every county unit and at the six clinical enhancement programs and the ones at the clinical enhancement programs are parents of kid with autism spectrum disorders and other developmental disabilities.

We have done an amazing amount of parent leadership development and training with these resources, including training a \*\*\*\* of now about 125 parents of children with a full range of special healthcare needs, including mental health needs as parent partners in medical home visits, so the concept of parent partner and medical home is having parents from within the practice, which is important and we're working with those parents as well, but we've got 125 trained parent leaders who can go into medical practices that are part of our medical homework and other counties as well to provide information about resources for families, to do trainings, to share information about how to partner with parents and also to be mentors to the parent partners from within the practices, so that is really exciting, a very diverse group of parent partners from all over the state. Yes.

Female: How long does it take to train those parents?

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DIANA AUTIN: So we—our parent partner training is a full day. It starts off with a full day training and there is a pre post test that is done of the parents as part of that training and there is—we recruited parents who already were part of our parent leadership, so they were SPAN resource parents that were already trained parent volunteers who go through an eight session training, so we started recruiting parents who already had gone through our eight session training, which includes resources and education advocacy and health advocacy, etcetera and then we invited them to come to our medical home training, so it's a full day training on top of parents who had already gone through this eight session comprehensive training around parent advocacy for children with special healthcare needs, but we also have ongoing training that we provide, so all of our parent partners are invited to our weekly conference calls with our technical assistant staff where there is ongoing opportunity to share barriers and what is happening and also to get professional development. One call a month is a professional development call about another topic, so we had a call around the Affordable Care Act for example where all of our parent partners were invited and then of course parents co-lead and participate in all workgroups and in fact we have a 50/50 rule which is we've got every single workgroup is at least 50% parents of children with special healthcare needs and that is important. It's important that they be co-lead by parents and somebody else because that sets the expectation. That sets the model. That makes no parent feel alone. Every parent has other parents. It's a powerful voice.

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And this was an interesting conversation because well we have so many other partners. We have hospitals and doctors and community-based organizations. Why should parents be 50%? Because the voice of parents has got to be heard and in order for the parent voice to be heard it has to be high in number. Parents always have support by other parents and if a couple of parents are sick and can't come to that workgroup you still have a nice \*\*\*\* of parent leaders that are part of the workgroup. So this resource parent leadership training that we do, which is kind of the lead in to the parent partner training talks about all of these topics. I'm not going to go into all of them. They're on your slide, but those are things that we do as part of our integrated systems work. We provide that training and parent leadership all over the state and we make sure that we do it within underserved communities as well.

Another focus of our work is adequate insurance and in New Jersey we have a lot of insurance resources for families. We have Catastrophic Illness and Children Relief Fund, but up until recently the only people who were accessing that were white middle class and upper middle class families and now because of the work that we've been doing around getting this information out to underserved communities not only are we ourselves connecting more and more families to this resource, but they are now doing advertisements on the sides of busses in Spanish and advertisements on busses in urban communities, things that they were never doing before and so we're really making an impact on—we are able to identify for the state that look who is taking advantage of this program and changing who now knows about the program and who has access to it.

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JOSIE THOMAS: Could you describe just a minute about this catastrophic illness fund because there are only two states that have this?

DIANA AUTIN: So what happens is that this is a fund that is available and people pay it as part of—it's a surcharge on something, which it might be the Motor Vehicle Tax or whatever. I think that's what it is and it goes into this pot and it's available so that family who has to spend more than a certain percent of their income in out-of-pocket expenses for their children with special healthcare needs can get reimbursement for that, for those funds and so it can be anything from making your house accessible if you have a child who needs to use a wheelchair. It can be for operation expenses. It can be for—we've helped families be able to buy accessible vans because of it. One of the other things is that it used to be you always had to purchase it already and then get reimbursed for expenses you already paid and we were able to work with the state to say low income families can't buy the accessible van first. They can't make the modifications to their apartment first and so we were able to work with the state to be able to accommodate families who needed to have some—at least some initial upfront money before they were able to do that and then get the reimbursement.

JOSIE THOMAS: And if you're interested in learning more about this if you just Google Catastrophic Illness Fund New Jersey the website has the legislation and documents and everything, so that if you want to copy it for your own state.

Female: What is the other state, Josie that has it?

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JOSIE THOMAS: Massachusetts, but it's not as robust. The third one that has something slightly similar is Michigan, but that's a trust fund and it can only be used for certain things, but this—New Jersey's is really unique.

DIANA AUTIN: It's really outstanding and now a lot of families know about it, so we're making sure families and health providers are aware of resources like that and so we have—we've created some one-page factsheets for providers, for doctors, for federal qualified health centers, for childcare providers, for community-based organizations, for family success centers, which is our primary child abuse prevention programs in New Jersey. We're getting this information out to all of these agencies that aren't just about kids with special healthcare needs because you know what, until families find out about the resources for kids with special healthcare needs they're not there. They're at the Family Success Center. They're at the Hispanic Directors Association Agency. That is where those families are because those are the community-based organizations that serve them, so we have these one-pagers that are if you're working with a family who here is early intervention, here is preschool special education, here is what SPAN can provide, here are the resources that can help, here is special child health services, etcetera. Very easy to use because providers don't want a lot of detailed information either. They want to have something quick and simple that they don't have to read for an hour and a half before they know what to do with the family.

We also have—we've partnered with our New Jersey Hospital Association to get funding to actually go out and work to enroll

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immigrant families whose children were eligible for Medicaid and our children's health insurance program in New Jersey, which is called New Jersey Family Care because many immigrant families who the parents may not be eligible were enrolling their eligible children, so we are working intensively with immigrant families and again our family staff on that project speak nine languages and then we're doing advocacy to expand and enhance coverage and that is something we can do that Title 5 can't do. We are part of New Jersey's Healthcare Advocacy Coalition and I'm saying we just joined a lawsuit against our governor who cut off all immigrant families who hadn't been in the US at least five years. These are documented immigrants who hadn't been in the US at least five years from coverage under our New Jersey Family Care even if they were eligible economically and we just joined the lawsuit against that because that is advocacy to expand that enhanced coverage, so some people may not like us about that, but I'm a lawyer, so I think that's great. Sometimes you got to sue them. You got to know when to sue them. No, okay.

And then awareness of health financing resources, so when we do our comprehensive health resource parent training we talk about the medical home and health coverage and how to get services and we talk about family care. We talk about the requirements for early periodic screening, diagnosis and treatment. Look at that. I didn't even have to go EPSDT. I'm so proud of myself. And the focus on immigrant families who in—one of the things when we did our proposal is we looked at all the sub data, not just what the outcomes look like for all children on the six core outcomes, but what do they look like for families who don't speak English. What

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do they look like for immigrant families? What do they—for Latino families and African-American families and low income families and moderate income families and so we said you know what, the kids who are having the worst outcomes in our state, the kids with special healthcare needs that are having the worst outcomes are immigrant kids and African-American kids and so we have targeted activities that are aimed at immigrant and African-American kids and connecting them to resources, so an early continuous screening or initially in our state implementation grant number one. This was we were doing some work around screening, but not a lot because New Jersey has one of the best rates, best response rates on early screening, early continuous screening in the country. We're one of the highest rates in the country, so we said we could still do more, especially for underserved families, especially immigrant families are not found early and okay, but when we got the second, when we were going for the second grant we said you know what, kids are diagnosed late with autism spectrum disability disorders in New Jersey and so we enhanced our focus on early and continuous screening with the second grant to work with pediatric practices around implementing screening at earlier stages to be—consistently and using appropriate tools that had some evidence behind them, so advocating for the use of standard routine screening tools and then informing families and providers or screening resources like early intervention and EPSTD.

In terms of easy to access community services we are working to make sure that primary care providers are aware of community resources. This is a wonderful thing that our family parent partners

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can do. They can go into pediatric practices and tell them here is resources for kids with autism. Here is resources for the full range of kids with special healthcare needs. Here is how you connect to early intervention. They can actually go on the ground in a way that you couldn't afford to pay a professional to do and these are parents. We pay them to do this, but we don't have to pay them the same way you would have to pay a social worker or whatever. They're excited to do it and they go and do it to their own practices, which is exciting too.

Our family resource specialists in all 21 counties directly connect families to resources and community services and we also are doing mini grants. Our local—Yes.

Female: I was just wondering how much you pay the parents to do that?

DIANA AUTIN: We do—we pay them on a per diem rate and that's—we pay them \$100 to go and meet with a pediatric practice and share resources. We also pay parents to come to our quarterly meetings and to participate in our workgroups and that we pay them \$35 to do that. The \$100 includes getting to the pediatric practice, etcetera, etcetera, so. We also have mini grants. Yeah.

JOSIE THOMAS: I just want to be careful about the language of paying parents. It's really reimbursing parents for their time, childcare and transportation.

DIANA AUTIN: Exactly, correctly.

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JOSIE THOMAS: You know it's not I'm going to pay you \*\*\*\*.

DIANA AUTIN: It's a per diem. It's a per diem to recognize the fact that—we don't want them to be worse off because they're doing this.

JOSIE THOMAS: Because they're doing this.

DIANA AUTIN: That's right, exactly.

JOSIE THOMAS: I don't want it to come out of their pockets.

DIANA AUTIN: Correct.

JOSIE THOMAS: So I want to make sure that your transportation is covered, your childcare is covered and if you had to take time off of work to come we're compensating for that.

DIANA AUTIN: Exactly. And then we're doing mini grants. Now the way we're doing mini grants is you have to have a community-based agency, a health provider and a parent organization or a parent group. If you don't have all three of those things you're not getting one of our mini grants and all three have to sign off on it, so we have got some great mini grants where we have—one of the things that is most exciting is there is a developmental pediatrician who has some resources where they can on a laptop consult with a school district around a kid that has autism or other developmental disability and what they wanted to do is they wanted to be able to buy some additional resources in order to expand the number of families that they could help. \$2,500 and they were able to quadruple the number of times that they were able to provide this

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service to schools to help them at an IEP meeting, so it's—and also give training to school staff. A little bit of money goes a long way, but they had to have parents that were part of that that wanted that to happen because that had—it had to be that partnership that was going to happen.

JOSIE THOMAS: For those of you who have the capacity to put this in your budgets to do it for, for example, you. I mean this might be something you might want to do to trigger some innovative practices in communities. It's a little bit of money and by golly people are creative with it. It makes a huge difference.

DIANA AUTIN: We're giving our county—we have 15 family support organizations that help families of kids with mental health challenges in our state. We're giving each of them—five of them each year because it's a three year, five of them each year \$2,500 and they're going into schools in their county to share resources on kids with challenging behaviors including mental health, but also autism spectrum disorders and other developmental disabilities that is aimed at reducing suspension and expulsion and reducing calling the police for this kid's behavior. \$2,500 and we're getting these family's support. By the end of three years they'll have talked to every school district in the state, which is fabulous.

We're giving a small grant to parents of autistic children to do workshops for early childhood providers on how to see red flags in child development and how to talk to parents if you see something that you're concerned about and then resources, so we've got all these kind of small grants that we're giving to organizations that are having big outcomes.

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In terms of medical home we're working—we're going to over three years be working in nine counties. In everything county we're requiring there to be at least one children's hospital, one federally qualified health center and four to six other pediatric or family care practices in the county. We've done one \*\*\*\*. We've just finished starting with three counties in the south and we're getting ready to move into Middlesex County. Parents as partners on the medical home teams and really trying to expand the use of the medical home tools and I could talk about that forever, but I want to talk just briefly about transition to adult life.

We have done a lot of focus groups with doctors and parents and youth about transition and we have developed a tool with a small Champions for Progress Grant, an interactive CD for youth around transition and it's really great and but doctors told us, "We don't want that." "We want hardcopy resources." "Don't make them stapled." "We want to know who does what around transition in the state, so that we can pull it out, make a copy and hand it to a parent or getting ready for the visit we can pull it out, read it and be able to talk about it with the family." So we did something that we called transition resources for health practitioners, which is it's not stapled. We mail it. It's also on our website. We mailed it to every pediatrician in the state so that they've got it in their file folder and they can just pull it out and use it and it's really great, so we're just using the resources to disseminate existing transition tools like that, but we're also developing additional ones. We worked with our university Center of Excellence to develop a manual or a guide around health transition for kids, which is really

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great, which is available in English, Spanish, hardcopy, on the website and orally on the website in English and Spanish, read out loud on the website in English and Spanish. It's great.

We're working with a federally qualified health center that is at a children's hospital that serves a lot of immigrant and African-American families to pilot some transition tools about the transition from pediatric to adult healthcare and working with a wonderful doctor named Dr. Steve Marcel who is our champion on that. We're doing training and technical assistance for families doing workshops and every county and we've just started a statewide youth council with 25 youth and young adult members with and without special healthcare needs because you know what, the youth with special healthcare needs told us we don't want to be by ourselves, we want to have a council that includes our friends that don't have special healthcare needs and it's working. It's fabulous and they've got—they're starting—they've got a Facebook page and they're developing a website for themselves, so in our plan we're developing a map. We're looking to see how others have addressed it. We're facilitating these stakeholder workgroups to identify strategies, implementing solutions and we are partnering with the central New Jersey Maternal and Child Health Consortium to do an interactive evaluation on both of our projects.

This is just what our performance and the core outcomes was on the survey and we have lots of participation opportunities, learning collaboratives, our quarterly meetings, 75 plus organizations. Now it's 80. We have monthly medical home leadership action group

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conference calls, periodic workgroup meetings that meet in between the quarterly meetings that we usually have. We have five different workgroups, including a health information technology workgroup and our director of the two projects whose a parent just got named to the Access Consumer Advocacy and whatever—Concerned Subgroup of our state health information technology thing, which is fabulous because consumer voice was nonexistent.

So I just want to say some simple tips to close for state agencies and family organizations, both of us, to be present, to build relationships, to be flexible, to be responsive, to be insistent, follow through offering a variety of opportunities, sharing the vision, thinking always about enhancing capacity and I'm telling you sustainability is all about enhancing capacity of families and family leaders because they're the one who are there after the money goes away and providing support and resources, which isn't so easy to do.

So I'm sorry to say we have like one minute for questions, but we'd like—

JOSIE THOMAS: We have 10 minutes.

DIANA AUTIN: So that was our presentation time. Well you should have said one minute for your presentation and ten minutes for questions. Well that's great, so now we still have 10 minutes for questions, so that's wonderful.

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JOSIE THOMAS: So we gave you a picture of a small parent organization doing what we could and then the Cadillac of what we aspired to.

DIANA AUTIN: I don't know if I'd call myself a Cadillac, a Subaru Station Wagon. How is that?

JOSIE THOMAS: Okay a Subaru Station Wagon. I learn so much from you every time.

DIANA AUTIN: So what about questions, comments, thoughts anybody has on—as I try and find what I just erased? Anybody have any? Yes.

Female: So we're—I'm from Colorado. We're talking about healthy \*\*\*\* and we had \*\*\*\* resources \*\*\*\* all the R&Rs that exist and making it more efficient and effective and so the parent volunteers that you have that seems like it would dovetail so nicely with like the initial triage and R&R network, but then following it up with parent volunteers that actually can go deeper into navigating and helping via \*\*\*\*, so do you have any kind of—are you working at all at that Help Me Grow level and partnering and working to \*\*\*\* parent volunteers with some kind of coordinated system for New Jersey or?

DIANA AUTIN: Well we don't have a Help Me Grow. We're not a Help Me Grow state. We do have—we have a single number that both in terms of early intervention and special education that parents who have concerns about their children's development can call, which is actually housed at a state agency, but really in many cases our organization is that one stop because families no matter the issue is can contact us and we have resources and trained staff and

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information on our website about that no matter what the topic is and we're on—our organization is on like the early intervention referral and the parent's rights booklets and every family who comes to our county special child healthcare services case management units gets the brochure that—our brochure that talks about the resources that we provide and we get many, many referrals from the state agencies that—the state agency that does that kind of they're the single point of entry into either early intervention or the Child Find kind of number.

We also have very strong relationships with the Childcare Resource and Referral Agencies and we have one in every county in New Jersey and so we actually have a grant from our state to train the Childcare Resource and Referral Agencies around talking to families who have kids with special healthcare needs, rights, red flags, resources and also we do onsite training and technical assistance to childcare centers around all of those issues and also how to include children with special needs in childcare, so we also have a very good relationship with those childcare agencies that get the calls for childcare. They get the call for the—for the childcare vouchers from the block grant. They get the calls also for some of the other—some of the calls for other resources and I'm blanking out right now, some of them. They're not traditionally around childcare. They're around early childhood.

A lot of stuff in our state is done by county and so having the resources—you have to really have the connection with the resources at the county level, which is unless you're looking for Child Find and then you can get that 1-800 number, so but one of the things that is great is that because we have these parents that

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are in every county our family resource specialist is on every county's transition workgroup whether it's the young transition or the older transition and we have families in every county that are on all these advisory—our Human Service Advisory Councils and which make decisions about funding around childcare and early child in each county, etcetera, so having those resources there is really great.

We wanted our state when the new thing came out we said to our state we should really apply for this, but our state didn't want to, so we-

JOSIE THOMAS: We would love to have a parent in each county. We don't have the funding to do that, so it's much more difficult for us to be able to affect change in each county and to work in that way, so you know money to come down our way would be really nice to be able to do. It makes a difference. We recently concluded some focus groups with parents and one of the things that we heard over and over again is the location of the center. If you're here and I'm here how can I get services from you? So having some of our staff in each county would make a huge difference.

DIANA AUTIN: And we actually used three grants to make that happen because we use our—our state gives you money to do it. When we rewrote for our Parent Training and Information Center for the five southern most counties we took one FTE position and divided among and house our PTI staff in the county case management units and then used the integrated systems grant money to fill out the rest of the county, so it has been really great and then we try to connect those

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families. Sometimes parents want to work part time. Sometimes parents are on multiple grants because parents might need to have fulltime work or more work than one day a week, but it really connects—having that family in every county really makes families feel like we're everywhere, which we really feel statewide now by having a parent in every county, at least one parent in every county. Yeah.

Female: You said you have 60 staff.

DIANA AUTIN: Yes.

Female: How many of the staff are parents?

DIANA AUTIN: All, 100% of our staff are parents.

Female: Okay, so \*\*\*\* staff that are parents and some that are \*\*\*\*.

DIANA AUTIN: All of our staff are parents and all of our SPAN resource parents are volunteer parents. They're all parents. We do open our training to community-based organizations that are close partners so we have had federally qualified health center staff, family success center staff. We've had Hispanic director agency staff come to our—train the trainers, our full day training and then they go out and are able to deliver—provide services to families. It really expands our capacity and makes their staff much more effective. We also have 40 workshops on our website that are in English and Spanish. Well some are. Like 30 are in English and 10 are in Spanish and we've have them on the website. The MP3 file is on the website

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along with the PowerPoint and the handouts and we send out—to all of community-based partners we say all these workshops are on our website. We encourage you. You don't have to ask us to come and do a workshop. You can show the PowerPoint on your screen, play the MP3 file and hand out the handouts whenever you want to and we do them live first, so we do an hour teleconference followed by Q&A, so the MP3 file has the presentation plus some good questions and answers and so we've had over 200 community-based organizations last year did workshops using that.

Last year 26,000 people listened to one of our workshops. This year in the first six months alone 32,000 times they were downloaded and a lot of the Spanish ones, but partly we connect Spanish speaking families to the web through Traducela Ora and a parent guide that we do about how to get access to online at your library, etcetera, so it's by having those kinds of resources and those connections the community-based organizations do the work for us, so it's we're impacting professionals as well as parents.

You had a hand in the back.

Female: Yeah, \*\*\*\*\*. I guess I was not listening very well, but did you say that \*\*\*\*\* care coordinator or care \*\*\*\*\* in your \*\*\*\*\* or what \*\*\*\*\*?

JOSIE THOMAS: No, we're working with the FQHC, but we don't have-

Female: \*\*\*\*\* you didn't-

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JOSIE THOMAS: We did not, no, but we linked—one particular parent staff is connected to them and works directly with them, but they're not onsite.

DIANA AUTIN: We actually have our staff who work with our CHPR Immigrant Outreach and Enrollment Project and family resource specialists and our trained parent partners. They actually go onsite to some of the federally qualified health centers and some of them are there like a day a week or a day every other week. They're not care coordinators okay. They're family resource specialists or parent partners or CHPR Immigrant Outreach and Enrollment Family Resource Specialists, but they're there to provide resources and provide direct support to families.

Female: I want to thank Diana and Josie. Unfortunately we have another round of session to \*\*\*\*.

JOSIE THOMAS: Great, thank you so much for coming and for being so generous of spirit as we struggled with technology.