

AMCHP 2008 ANNUAL CONFERENCE

WE ARE MAKING A DIFFERENCE:

Evidence-Based Practices for Organizing Family-Centered, Community-Based Services

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EILEEN FORLENZA: That has some technical assistance some ability of to move this along and that happened to be me in this particular instance but it doesn't always, it's, sometimes it's people that you have to look in the [inaudible]. But I think that's the key part because it ties it in to the short [inaudible] of Title V. And then also it happens [inaudible] and you can really connect to the pulse of the community of what's going on. It's important that whoever the champion is, and I say champion that, those have to change, but something that we invest in. not just the involvement piece. Someone who has the tenacity and the leadership and the vision to say, this is where is I want to be five years from now, that can move us into that planning piece, which goes back to the consistency principle that Debbie talked about.

Looking on at policies and procedures, finding a way to make this doable, having that can-do attitude. I'll give you an example. We just shifted into a program down in Denver. We started with a program in Mount Rosa and then the Colorado Springs area decided that was something we wanted to do. They put out some newsletters and some notices and there was going to be a community, around creating a community-based

Respite Program and the first night there was 73 people there just [inaudible]. Isn't that amazing? It wasn't just families, it was if you're saying the Department of Health, the human services and [inaudible] communities, the developmental disabilities community was there, the [inaudible], the objects of society. It was an incredible showing which took us back to kind of just knowing what needs assessment and having a pulse and understanding of what families were looking for. So having a, having a shared vision of obviously in that case in Colorado Springs of knowing there for 70 plus people that were interested, but you gotta be able to assign somebody who's going to put this into action. I just love looking at diversity. I love being able to assure that the diverse perspectives are involved in every layer and I contend and a lot of people in here will recognize that one of the strategies we're doing at is assuring the campaign with participation.

Family participation brings the diverse perspectives and it brings a lot of different strategies to the table but having an inclusive format, what people did to the Denver area, the program did, we knew right away through working with one of our non-profits [inaudible] which is a non-profit agency that served [inaudible] families, who have children with special healthcare needs. And we we're told that when this respite program was going to come out, there would be an incredible deluge of families that were looking for this service. We also knew that we had a high incident rate of [inaudible] with autism in the Denver area whose seeking some support. So to that in place, we made sure that as part of our team planning, we had representatives from [inaudible] for intake and for [inaudible] of the entire planning process [inaudible] but also we have autism specialist on site at this Denver Respite Program. The Respite

Program is a six- hour long break, by the way. This is not two hours like a lot of respite programs tend to be. It's for six hours so that families seriously have a chance to meet their needs and getting away and finding some coping mechanisms on their own. What [inaudible] in our original site in Alamosa we noticed that during that six hours, in fact the first hour and half there were families that just keep hanging around in the parking lot, and there was coffee, and [inaudible] trying, and how's your diet going, [inaudible], so what we decided to do was refer a parent education piece into that program.

So supporting the needs of families because of [inaudible] from about six counties in the southern part of Colorado, so we have a parent education component. So the first two hours from 4-6 pm was just family education. And that actually opened up the whole new funding [inaudible] for us. We we're able then to access different funding groups because we were doing parent education. So then we have speakers in on nutrition or behavior modification type of things. So that was responding again to the unique part of that community. Again, taking a look at how can we take this from an idea and a thought and a need and really moving into implementation was staying committed to a plan. My plan, for example, was I wanted to replicate this across the state on a three-year timeline. And not having that attachment necessarily to how that happened at the community level 'cause those community coalitions were unique and special to themselves but the, but my timeline for the state was looking at how we were going to grow this and then leaving the actual nitty-gritty, nut and bolts to the community and that kind of touches on the role of government.

What is my role at the state level as Title V? My role was to share the vision and to give some of the framework of how this could work. But then I could step back and let the community do it in a way that works best for them.

The sixth step was, again keeping the program [inaudible] and keeping the values of the program in place that somebody being able to say, wait a minute six hours is really important. We have some communities that said, well that's just too that's just too long. We can't get providers. Oh, I'm sorry but that's only the values that their families and some of the other successful programs had indicated. With the two-hour respite program, two or three hours, I think it really was actually more stressful for families is what we found at the time the equipment was right in and getting the things self figured out, we knew that we needed this six hours span of time. One of the other value statements I should mention is that one of the sustainability pieces of this particular program on, is that we use students from the local colleges to actually staff for the rest of the program. We have a program in Milton, Colorado that we have three universities that provide nursing students, we have the Community College of Denver, [inaudible] Community College and Frides and all three of those universities have nursing and general special [inaudible] programs and they're the ones that are providing the staffing. Staffing is almost always the biggest hurdle to get through on a community respite program so we took care of that. And that's something that we really hold true to in terms of when we're replicating the program. They're finding outcomes and measuring outcomes. You talk about that being something really important. The respite program was an example of, we went into thinking our entire goal was to simply support families

and to give them an opportunity to just normalize their day however that might look like for them. What we found was that the outcomes were so much broader than that. We started to pick out the points that we felt were important. For example, the program down in Alamosa when they were using their students, they were pulling students from the nursing program and their special education and general education programs. What we found is that 25 percent of the students that were there that were actually provided the respite, 25 percent of the students switched their major from general Ed to special Ed after about three years in the program.

So, when we talk about strategy that then allows us to get [Unintelligible] from Power Department Education from Special Education Division on the recruitment strategies for professional drawn. So, they are a lot of little pieces of outcome that we want to setting. Another one was in the Roof Communities we learn that the programs that we're addressing youth that had the age group that including the teenagers that this coalition should realize that this was one of the only one social opportunities that kids with high needs really had. So, voted into your IPs and so the planning group came around and the youth that were actually tending the Respite Program from behind of the registration table they were clearing off the crack table so, we built those Skill Sets and into their IPs as part of what we've working on in then the transition plan and then guess what happened? so then can they change for that the collaborative move was that the school donated their school buses to drive to the outline counties to pick up these kids, is that just phenomenal?

So, those are examples of coalition and what we learned at that state was that often to whole communities that they bound together, they know what you're doing and we need it to learn from them about how to make sure what are the things happen and talk about it all of the time we have got to mold at the state what we're asking in a local communities to have to think and if we don't do that well and if we don't talk to everybody that we actually share a building with them, how could we modeling and that you're your name ad McDonalds. So what we've realize it is, just a simple Respite Program we were able to extract the outcomes at the family level, a community level and actually the child level. At the child level what we've found was that again I gave you the example of the transition plan but also that the younger children we might have had some behavioral challenges. It was an opportunity for them to work on some of the socialization and once we've raise awareness and call the [inaudible] and said this is an opportunity for really to understand to take turns and we can anticipate the [inaudible] that we learned in next month and they're going to be probably find with the same toy and we're going to work on this, it is a different setting tools, it's a different setting and a clinical setting and it was a completely community setting.

So what we learned is that we start when we do intake with the family we ask them, are there some things you like us to pay attention to in terms of friendship building and that's for [Unintelligible] so we've started to track just a few of a trial outcomes and that was been helpful with the families we've found again that often times it's should simply the coping mechanisms, what are you doing, how's this impact with your family life, on passionate around or sibling relationships. We asked a few questions about how the

siblings? Do siblings come to the rest of the program? Do they choose not too? My youngest son who is nine loves to go and he just go since [inaudible] and anyone that sibling opportunity for siblings to talk to other siblings about what is like to being love with their sister or brother life special health care needs.

What we also found was that the families use that time to go to work [Unintelligible] about a lot of Noting Colorado Program we have a lot of families who owns small businesses or have a lot them continuing any kind of opportunities and then used that time to do that. So of course we've bumped that up and talk about economic stimulants, economic development and how to launch the entrepreneur and all of these things are kind of family support or oriented. And then the community are regional offices reported that all programs and we thought it's just a day or that this gave them an opportunity and excuse a reason to get in the same level when someone or other agencies that they typically [inaudible] in our way and I'd think let me use that this morning about sometimes with the same ability just could being people together is one set works with the same ability and understanding that we do exist for the share or vision. And how you come around to support the family and leading for way. So that's was some of those outcome measures were focus around. This is just a quick glimpse of how our state is divided into the regions that we have local offices, you know, we now have eight Respite Programs that within all of these well I don't have a dotted out here but you can see that our other than the detrimental area which is the red piece in there.

We have a very diverse and a very broad area to cover in Colorado and the Respite Program the community coalition that develops from that were all very unique and we've learned from one another but we are able to allow the coalition and the community to define what works best for them and they all have named different things and they have different flagging, we've got the \$40,000 grant from one of our locals, we've gotten grant from department Of Education. And my role is to come in and do consultation and help them to get started if they're unable to step out of the way. Some of this spins off including the, mostly it's now [inaudible] boys and girls club and we have three site in the Denver area that are now run by the Easter Sales Program of Colorado. So there's been a lot of really nice community outcomes in that way. This was just a reminder that we have to develop the, after we developed the coalition and this was some of the outcomes that were looking for and they were not specifically again that families will get a break our data was not to say how many family that you've start with, which one is zero and how many families are we now serving now that was not just the only data we are looking for and I'd think that's it for now.

KATHY WATTERS: Well, as promise we're just going to mention a few other coalitions again if you don't have a Respite Care Coalition in your state for a lot of other topics, needs, issues that communities are facing and pulling together if you stay [sounds like] stakeholder to begin to tackle those problems, to bring together, to develop plans, to implement and then to measure your progress as a Respite Care Coalition illustrated. Our Newborn Hearing Screening Follow-up Coalitions are beginning because we see that some areas have difficulty with follow-up and Vicky Thompson is our champions

and she's out there in communities looking for a Physician Champion in families, in hospitals to tackle that issue and then will be working on some Medical Home Quality Improvement Coalition and that's relates to the action guide that I wanted to point out to you and then will end and answers questions.

The action guide hopefully you all got a copy was one of the handouts on the table. I want to give credit to the National Adolescent Youth Initiative who drafted this action guide and then Adolescent Health Coordinator took the action guide and revise it and then the National Adolescent Initiative adapted the Colorado revisions so that's you see this action guide is a tool that we're using for local planning for our Children Special Health Care Needs Programs.

And you'll see that in this action guide we started off with, this is placing the [unintelligible] in best practice guides this seemed to be a tool that much easier flow, much easier to read and on the first page we can illustrate all the data that goes in to building a Medical Home System this is an action guide for Medical Home Approaching System for Children Special Health Care Needs. We start with the data and then we have three strategies for really planning for local implementation in medical home and then the first strategy is leveraging strengths and assets of partner. So the first strategy we're beginning to talk about to build a Medical Home System for kids who special needs in communities the first strategies to look out the coalition who're key staff folders ,who do you bring to the table. The second strategy is utilizing family leaders...

EILEEN FORLENZA: And the reason we wanted to make sure that this was maintain is again utilizing the family leaders with so many different components to the table it belongs so strongly in the culture of diversity that family can identify the needs that family is very culturally diverse way. The family leaders that come in also are generally free to help identify gaps in your systems as well as offering recommendations and solutions in a way and that's a different perspective from the agency representative. And one of the things that are often talk about with family leaders it says the family piece is a consumers voice of what we've doing and the consumer voice is a public in the public health and so how we can move into an area of a sexual to public health without hiring [inaudible] public representation that's purely for the consumer voice it is something that we think about to looking at another game all the assets and community.

KATHY WATTERS: So, the third strategy we've identified was connecting with the Local Primary Care Providers and Special Care Providers that was really made of strategy for us too but again it's a comprehensive planning with coalition building is a major strategy for us hearing out this plan. The client part is an opportunity is to list your resources and tools. For we did want to share with you a tool that we're feeling pretty excited about MCH director is here too and let's you using the tool across all in state program so that's very exciting and we are making the difference.