

AMCHP 2007 ANNUAL CONFERENCE

HEALTHY COMMUNITIES

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Title V: Helping to Shape Healthy Communities

LINDA HAMMON: I'm Linda Hammon and I'm from Arizona and I am a parent. I had one biological daughter born to me with cerebral palsy and that was 30 years ago. And so that sort of started a whole new life for me. At that time I was a preschool teacher and it was totally unexpected, like most of us. So I started this whole journey.

And then I started finding out that there were so many children who were being left in hospitals and who did not have the opportunity to have a family and a home due to whatever circumstances medically were necessary. And I had some medical background and so I convinced my husband that we had three biological children and that we didn't have enough children and I could no longer have anymore, so we became foster and adoptive parents. And so we've adopted four children with special needs plus my three. So we have seven children.

And I'll get this up here. And so it started a pretty long journey for me in which I needed to learn systems really well knowing that in fact that the only way to really advocate for my children, which was to learn the systems as the best that I could and understand them because 30 years ago there were waiting lists. There

weren't entitlements. There weren't a lot of the things that you as parents, younger parents I should say, have the ability to have.

And so I felt like if I knew enough when they told me no I could actually respond intelligently to say in fact, no, wait a minute I think the system could accommodate that and if there was a creative way to do it, then that's what I was going to do. All right, we're finally there. And so that sort of started my whole journey within this whole world.

And so I started out when the Department of Health took on the position of having an office for children with special health care needs within Arizona. And they started right away with looking at how they could partner with families, which at that time is very minimal. You might be on a committee, but nobody really listened to you. What we call it is sort of that token parent where you're in the room and they fulfilled their family involvement. They don't really want to hear what you have to say, didn't really care how much that meant.

But within the Department of Health Office for Children with Special Health Care Needs they decided that in fact they would start what was called a community development initiative and really partner with families at the community level as well as the state. And so I'm going to talk a little bit about that, also about our family youth leadership program and our parent led community action teams.

And then understand what role the Title V office plays in partnering with those families and within the communities.

So the goal of this initiative is to develop family leadership. Family leadership needs to be nurtured. It needs to be supported. It needs to have a place to grow. And the implementation and the collaboration is at the local level rather than at the state level. So it starts at the community level and then also goes to the state and the national level. And that families and agencies work together to strengthen communities to improve the quality of life within families and communities.

And so we started a program which we call our Parent Community Development Leaders. And these leaders are to develop partnerships within the communities, connect people and resources, really look at what's in the community, not what isn't in the community, which is always how our children were approached.

I remember my daughter early on as soon as she was able to speak said, "Why do they always start the meeting with saying everything I can't do because there's a whole lot of things that I can." And she was right. So we really look at within our communities and our families what are the resources, what are the assets that are already there that we can help them build upon and to promote community change.

Healthy people—healthy communities produce healthy people. Distressed and unhealthy communities produced distressed and depressed families. And so we really want a healthy community that embraces all of its citizens, not just the ones that community programs are normally aimed at—parks and rec—who wouldn't have a program for our special needs children, but for all of the families in that. And also just to provide that leadership, not only for the community partners but for the other parents.

And so about 12 years ago I started out as a parent leader, a parent community development leader within my community and that was in Flagstaff. Flagstaff is a fairly rural area. We do have a university there but 12 years ago there wasn't a whole lot of other things to really support families in the community. And so one of the things that we do for those parent community development leaders is agency support. We provide them with the support and technical assistance.

So from our office at the state level in partnership with those parent leaders we develop trainings, we have biannual meetings with those parents in which they develop the training for it. We support them. We do the copying, we do some of the technical assistance. We help support them to learn the skills to do that. And for any new leader we have a new orientation training that we do with them.

We also compensate them for their time. And right now we pay them \$15 an hour for the time that they engage work within their communities or at the state level in

partnership with us. We also give them reimbursement for travel. Arizona has a lot of rural area and so to come to the state level is—some people it's five, six hours for them to travel. So we reimburse them mileage, per diem, lodging if they need to come.

And then the other thing that we started doing when we started developing the teams is we realized that those community teams as they got started would need some organizational funding. They would need to have an administrative assistant. They would need to have a laptop, postage, the ability to copy or print brochures, take on those initiatives that they might find other partners, but there would be a missing funding source for them. And so we offer organizational support money. And this is all through our Title V Block Grant money. And this is how we've chosen in our state to really support the families.

This is a map of our state and these are the different teams. Right now we have 13 parent led community action teams and they're pretty well spaced out all over the state. Our two newest ones are up in the corner and that's Turtle Nation Partnership which Twyla Patema is going to talk a little bit about that in a minute. And excuse me; I kind of woke up this morning with some whatever, so hopefully my voice won't completely go.

And then one of our newest teams is called Quest to Cure and it's a little bit different because all of our community teams don't have any one focus, it's all

around in the community what are those families and children with special needs and youth. And that special needs could mental health, diabetes, asthma, development disabilities, the gamut of that.

But we had a family team come to us who were basically a family support organization around sickle cell anemia and saying there's not a lot of services in Arizona for sickle cell. And of course Arizona is a very fast growing state with people moving from back east and so probably a few years ago we had relatively few families with sickle cell. And so they said what—could we develop a community action team specific to sickle cell. And so we thought well, we're moving forward, a different model. However, those families are so dedicated they're pulling in any other families and it now is primarily sickle cell but I don't think it will be that way long. And that's in our very metropolitan Phoenix area.

The key principals of this initiative, of the community action teams is that they are parent led and agency supported. They choose what initiatives they want to work on. They choose how they organize their team but it's based on principals of family leadership, looking at resources and assets within the community and being inclusive to all the families within the community.

One of our teams, they pull in a lot of community partners as well and one of our teams, the local mortuary said we'd really like to support your team. And of course everybody said well, I'm not sure how that fits, but we'd love to have you.

And they said well we feel like one of the things that we do is support families at the end of their journey and we'd like to support them at the beginning of their journey. And we thought that that was extremely wonderful to think that a mortuary would think that. They provide food, which with Block Grant money it's difficult to pay for food, and so that's been really an important piece.

And the key principal is that the families are doing the work of the community, not the work of the agency. We have families that come at a state level and help us do the work of our agency, but in the community it's about doing the work of the community. So it's what the community feels like that there's a need for. And that changes conditions that affect people, not changing the people to meet what the program is.

And we feel like that's a huge point to remember is that—I also remember my daughter saying in some of her IEP meetings saying to me, you know I leave there and I feel like they think they need to fix me. I don't think I'm broken. I have some really different things that are challenges for me but I'm not broken. And we feel that way about our community teams. They're going to change the conditions that affect people but not look at changing the people to meet the program. And so that's a very different concept that our family leaders take on. And that communities become communities again in which they are all looking out for all the citizens within the community rather than the little pockets.

And so these are members of the community team. And the picture there is one of our parent community development leader's son and Ryan is about nine now and his goal is to be a police officer. And Ryan has down's syndrome and so Ryan decided that as a part of his role within the community team that he would engage those police officers to come. And so they actually have an initiative that I'll talk about in a minute about that.

But the members is everybody who wants to be in the community team. Most of the teams have their special ed director. They have social workers from the hospital. They have administrators from the local hospitals, the Division of Development Disabilities, pediatricians, community businesses, city parks and rec, so that they can look at the whole gamut. And basically anyone who would like to help support the community teams.

And all 13 of them are very different. They look very different. And I have the pleasure of helping to support those teams so I get to travel around the state and watch what they're doing in their communities. And they're all extremely unique because no one's telling them what they need to do.

We don't say to them at the level—at the state level you need to take on this initiative and change that. What we say are there are the six performance measures for children with special health care needs and those are the things

that we're responsible. We want you to help us in those areas. But how they do it and what initiatives they take on is completely up to them.

The benefits of community action teams that families and the community members take on the responsibility for not only the decision making but for all of the actions. And so they gain ownership of what they're doing. And if we all know if we're told to do something we're not as likely to be as passionate and invested in that as we are when we decide what it is that we're going to make changes within.

It's also a prevention approach instead of a crisis management. Typically within our agencies one of the things that we do is we're putting out the fires. What are those things that people are screaming at us about and how quickly can I fix it for one parent, for one family. But the community teams are looking at how can we fix it for all of the families within our community rather than just one. And that becomes a whole different approach in terms of the amount of time and energy that you can put to solutions rather than complaining.

Efficient use of resources. And we have some very rural areas who—one of the first comments is we don't have a lot of resources in our communities. And we do a little exercise with them called the images of potentiality. And we say to them, what are the things within your community that you already have and what would you like to see different in a year. And it's really amazing the number of things

that are true resources and most of them are the families. They are the individuals who have different skills, talents, who would be willing to put forward in this.

But I think one of the basic important benefits is that it shifts the nature of relationship to collaboration rather than confrontation. And we typically do that because as parents we get angry about what we need for our child. We need therapy. We need whatever the program is, there's not enough funding, we're on waiting lists, whatever it might be. Instead the parents take on ownership of I'm part of the solution. I'm part of what's going to happen within our community and the services that are organized and the way that they're organized.

And this is also one of our newer teams and this is called the Turtle Nation Partnership and I have to say to you this is one that is my very favorite. The families are so dedicated and so wanting to make changes with their community. And Twyla's going to talk about her team and how that—you guys have been a team about a year. And we have a video if it comes up—there we go.

TWYLA PATEMA: Well good morning everybody. (Foreign language) that's good morning in our language. This is where I come from, the Hopi Mesa. I talked with several of you before saying that we don't have any, or too much resources. As you can see, you know, there's not really anything out there.

And so when I had my daughter, like I said there's very limited resources. And every time we had to have her go see a doctor it was a six-hour drive, a four-hour drive that we had to do. And people told me, you know, why don't you, you know, move away to the city where, you know, all that help is and I could easily have done that. But what I decided looking at the families, you know, that had their children already with disabilities, you know I was thinking they either had to move away, got put into some type of home or they kept their kids hidden, you know, in their house and didn't bring them out to the community.

And when I had my little girl I decided, you know, this has to stop. We have technology now, you know, there's all these resources that can be brought to our reservation. And so that's when I decided, you know, we need to come, you know, bring this stuff out to our homes. I can't, you know, move away because there's still other kids that are coming in. You know sad to say but there's families that are out there, you know young people that are out there that they don't know if they'll have, you know, children with disabilities. So that was my point.

And also attending some of these meetings when the ladies started coming out, you know we started bringing in people and some of them were older families that had gone, you know, through all this already. And so there was that interest that we had out there, you know, was to now longer send our children away, no longer, you know, keep them in the house hidden away from our community.

And this what you see right here is called our special needs activity day. It's when we bring everybody, you know, not just our tribe, but different tribes—this is the Apache tribe doing their dance—and we have everybody come out and you know you can see—I think we had about 500 people that day that came, you know, came to this special needs awareness day. So we can bring that awareness to our people, have them know that our children, you know, that they're special people and they can contribute to our community. And so that's what this is.

Well what we've also been doing is contacting our tribal council. We want them to understand that we are out there and that we do need services. We have an office of special needs right now that was established maybe in the late 80s also by parents because the tribal council, our tribal leadership, they didn't have any kind of department for our people. And so parents got together and they had that—they lobbied our tribal council and they had the office of special needs established which looks at early intervention and the voc rehab program but that's basically all they do.

And when we do need help, then they send us away again. And so with our group what we want to do is to bring those services back, you know, back to our reservation. So there's—you know there's a lot that we can do when, you know, we do that. And another thing is, you know, to have our own people service our

kids, you know, our people instead of having, again, to send them away. I'm kind of losing my train of thought here.

Also looking at the different programs that are—most of the programs that we have up there are under our tribe. And when I looked at those programs, they were—they just worked within themselves and they'd never really partnered with each other. So when we first had our—when we first started our team we named our team Turtle Nation Coalition Movement.

And I don't know if some of you remember in the 70s they had the AIM movement, American Indian Movement, and it was kind of like a militant thing. And so that's what people would tell us. Well it sounds too militant and so we had to, you know, back away from that, back away from that and then we looked, you know, back again, you know what do we want to do. Because what we wanted to do was partner with all the other groups that are out there and so we change the, you know, the part of it, the movement part to partnership and so—and then our new logo that we came up with is a hand, you know, a hand and it has a turtle in there just to show that we have that hand out there and we want to, you know, bring that partnership to everybody out there and have the different programs work with each other.

And into our name, maybe you're wondering why it's Turtle National Partnership. We were, you know, really thinking about what name are we going to give our

group, you know or thinking special needs or, you know, something like that. And one of our group members says, what about turtle, you know, a turtle. And we're like, why a turtle? And in our culture we think of a turtle as having wisdom and courage, strength and so we're thinking about that and so we were looking at that and then another person said, well, look at our kids with special needs, you know, they're kind of slow, you know, they take their time, but they do eventually get, you know, to where they're going at the end. And so you know, so that was one of our things that we worked into that too, you know, turtles is you know they take their time but they do get there.

And so one time I was out in the community, you know, trying to recruit people to come to our meetings and I was talking to this one lady and she's a native lady and I was talking, you know, giving her the whole thing about, you know, the story of the turtle and she's standing there, uh-huh, uh-huh. Then when I was done then she goes, but I'm Christian. And I'm like, oh, for a while I stood there and I was like, what can I say. Then I go, oh, you remember the story of the turtle and the hare? Who won that race? It was the turtle, yeah. So that's our Turtle Nation, our partnership.

So I was kind of, you know, dazed up here and it was hard for me to get things out, but if you want to know more about our group later on when we do the one on one then it's easier for me. So, thank you.

LINDA HAMMON: So you can see why that's one of my favorites and I was so happy to have Twyla be a family scholar this year and learn more about the partnership with Maternal Child Health.

I want to briefly just talk about one of the other initiatives. Our team that's in the Prescott area decided that one of the things that was occurring is that when any of our first responders, the EMS, the police, the sheriff, the EMTs would come, and there would be a young man with autism or someone who was deaf or mental health challenges and the first responders have their own little protocol about what they need to do and how they interact and talk with them.

And so if that person's not responding in the way that the sheriff thinks that they should if there's been a call, then they're going to go into their whole mode because they're going to think this person is dangerous when in fact this person may be nonverbal or now is freaking out because all of the loud noise and the sirens are there and what it might be.

And at the time I was still working in Flagstaff which is really close and they came to me to talk about what had happened to my daughter too. My daughter was 27, living on her own in her own apartment, doing quite well, had a job and—but she did have certain needs and one was—one of the issues that she had is her articulation sounded a little bit more like somebody's who's drunk and slurs their words and so frequently she would get asked if she was drunk and she also had

ataxic cerebral palsy so her balance was poor. So you pretty much have the picture of somebody who is intoxicated.

She called 911 one evening to say that she just knew she was not okay. So they came. They couldn't find anything wrong with her other than they're thinking she's probably drunk. We did have a card, but because she was feeling so poorly, she wasn't directing them to the card that was on the refrigerator. And the emergency personnel didn't really know what to do.

So she did—was able to give them our phone number, unfortunately we weren't home and they were able to get my son and my son said, you know, if she's telling you that something's seriously wrong, you need to transport her. They actually wanted to leave because they're thinking she's really fine, she's just drunk, but not drunk enough to transport. And she's trying to tell them the really awful headache that she had and of course they weren't really listening. But my son said you need to transport so they said okay. Well she coded within another few seconds and she passed away that evening. They had actually spent probably 45 minutes before they actually even were willing to transport her.

And so this program came about because of that and a few other stories that had happened which was to say that we needed to have a flag within the first responder program when the dispatcher called them to say there is someone there with special needs. Now because of all the HIPAA regulations you can't say

what, but it tells you that there is a tag in the front window. The dispatch tells them where the information would be kept about them and they go through a whole series of training, all of the EMS professionals that let's them know some of the things to look for and some of the ways in which they can interact.

We've also set up a program where there are telephone numbers of people within the behavioral health system, within development disabilities and other who could quickly give some tips on how to help. And this started in tri-city partnership which is in Prescott. It's now in several of our communities including Scottsdale which is a huge city in which that's being done.

And it's called a Smart Card, a first responder Smart Card program. And so now there will be a flag that comes up to the dispatcher. There's also stickers that are on the cards. And this has made a huge difference in a lot of communities to really—and the other thing was it really engaged all of those professionals to be a part of the teams in those communities. And so we really feel like that what we do at the state level to support those teams, they are doing far more work than we at a state agency could do with the money that we provide them. Thank you.