

2011 AMCHP and Family Voices National Conference: Roles for State Title V Programs in Building Systems of Care for Children and Youth with ASD and DD

02/15/2011 Omni Shoreham, Washington, D.C.

HOLLY WILLIAMS: I'm Holly Williams and I am from Utah as Barb introduced in Harper. I will be talking about what we've done in our state to develop and to work on developing a system for child and adults with autism. And I wanted to say we are no where finished and I can see ourselves in every single one of the levels of development that Georgia was talking about, so and I'm humbled to talk to all you guys I know who are also doing great stuff in your state.

The economy as everybody else has had the same situation has really impacted everything we've done recently and has really eroded a lot of the basic services. However, we're going to pursue anyway. These are some of our early partnerships and if any of you know Fan Tate, she worked with me for eight years and she kept saying, "Holly, we have to do this grant; we have to do medical home. It's the right thing to do". So I kept doing what she said. So we kept going, we kept going and went through several other grants which they became the building blocks for what we're doing right now for autism because it's the right thing to do.

These are some of our partnerships; they're certainly not all of our partnerships. The University of Utah Department of Pediatrics and Department of Psychiatry, Utah State University where Judith Holt works and she's another person that will call up and say, "Holly, you need to write this grant" and I'll say, "I don't want to" and she'll say, "It's the right thing to do".

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So anyway, she also did that same thing with the LEND 10 years ago with Fan and we also know it's a lot of work and she said it's the right thing to do. So we now have, we're in our tenth year of the regional LEND project and hopefully we'll get the next five years of help and that comes through the University of Utah.

Through all our grants and so forth, we've worked with primary care providers, not just medical doctors, but family practice doctors who have been more difficult to pull in, if you've had that experience, as far as training and providing medical homes for kids with autism but also all kids with any kind of chronic disability. The Utah Parent Center is the Utah Health Information; anyway it's the education arm of the working with families of children with disabilities. Then the Utah Family Voices and the Family to Family Health Information Center, Jeannie Pulamoney is half in our office and half in the Utah Parent Center office and then the Utah Council of Autism and Harper's going to talk about that. Good luck on this little thing.

HARPER RANDALL: Holly and I are tag teaming a bit; I apologize for that turnover.

That's sort of how we get things done in Utah is tag teaming. So we figured we do it with our presentation as well. Did you change; did I change. I know but you put me on the first slide. How do you get me further up?

HOLLY WILLIAMS: No, she's got the same presentation as we do.

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HARPER RANDALL: Here we go. Thank you. So I wanted to talk about the Utah Council of Utah and as Georgia so nicely eluted to, really it's that grassroots I think that has made efforts with all states in the area of autism so successful. There's just this passion that this group of people with those disabilities bring to the table that has everyone sort of pulling their eyes up from their paper and listening. And I think that is one of the main reasons any efforts that we've made in Utah has so successful is this council and when you go on their website, Autism Council of Utah, I encourage you all to do that, what's impressive is the way they describe themselves is an independent council working to foster collaboration, communication and learning among family and agencies. So they don't say we're a family organization and listen to us. They say we're part of the solution and you should be a part of us. And they had an amazing effort where they put a conference on on the need for faith-based organizations in Utah for families with disability and specifically with members with autism and if any of you are familiar, probably most of you are, there is a predominate religion in Utah and they made a huge effort to not have that be the focus of that conference. They invited representatives and this representative caught the bug and said, "Oh, my gosh this is huge. We should go forward with this and we should talk about this on the Hill." And she got a work group together and part of the work group was the Lieutenant Governor and we got all of the different denominations which is, I really sort of had some doubts when we started that this wouldn't be just the predominant religion, but it wasn't. It was everyone was at the table and from this a resolution came out designating the last week of April as Autism Disabilities

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and Faith Week to emphasize the need for faith-based organizations in the lives of these families and also the importance of educating those faith-based efforts. So they are wonderful. As well we now have Utah license plates through their effort; an autism license plate.

Two other efforts that actually the Department of Health or Title V was involved with, although we certainly aren't, we fan the fires but other people have taken them on, is the Utah Registry for Autism and Development Disabilities. It was created in this Children with Special – if you can go back – Children with Special Health Care Needs Bureau, in 2003, we helped get a reporting rule. In 2005, we got some building block money. That was something that we don't do anymore, and got some funding for this registry. They've been involved with CDC, with the Adam Study and now it's acutely housed in University of Utah. It's recognized by our legislature as the organization that collects information on autism. And our role is really an oversight to make sure that anything coming out of the registry is correct and then also arrange for additional memorandums of agreement for all of the agencies. So now we're in the process of getting Medicaid to deliver information to them. We have early intervention even though it's ***** limited organization, they now are providing information to this registry. So it's really blossomed.

And then my favorite autism, the Utah Autism Initiative. You can, great. Our then director, executive director of Department of Health had the foresight to say, you know what. Boy this is going

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to be a big issue here in Utah, let's get everybody to the table. And he created this in early 2007 and we have representatives from all of the major agencies that provide services for ASD. In addition, we have parents and advocates. And so we have state agencies, human services, education, voc rehab, but we also have private and community organizations and then URAD's represented, Autism Council of Utah is represented. We have the chair of the Psyche Department from the University on that panel as well. And what the initial purpose of this committee was to identify the services that are available and identify the gaps in those services. And what I didn't realize at the time when I first started being involved with this committee, is the importance of having everybody in that committees understand the same things. So now we're working with this foundation of knowledge and even though it was back in 07 we've only had one changeover in the committee membership. So people really interested, really involved, really wanting to make a difference.

So the plan is when we look at the services and the gaps, let's make recommendations. And a couple of the projects that we're currently working on is looking at all of the data, all the data systems that are available in Utah, early interventions, schools, Department of Health and seeing how we can, what are the limitations to sharing that data and what type of recommendations we can make for outcome measures that are statewide.

Another thing that we're working on is we just finished drafting a document that's going to be provided providers and to families on

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what people need to be aware about when they're considering both traditional and nontraditional ASD services and treatments. And what was the beauty of this committee is that because all the agencies were there and they all were involved in the drafting, they went back and they talked to their division heads and now we're getting all of the division head and department head logos put on this document and we're putting it out. So it has some meat to it. And again through the years, I think it's because of the years that we've both been together there's a huge amount of trust.

And the other thing that's wonderful about this committee is that even though it started as a Department of Health initiative, it's not thought of as a Title V; it's not thought of as Department of Health. It's thought of as an entity in the community that has to be at the table. So if there's any discussion that goes on about autism, representatives are there. And so the legislature just put forth a proposal before Medicaid to submit recommendations on what a autism waiver should look like. And Medicaid can often close a door and come up with a proposal and present it but they didn't. They knew we were an important entity, our members were asked to be involved in this work group and together we created this autism waiver which I think was a great, it was very important. We had family representatives, of course, at the table and unfortunately we did present it in October and haven't heard anything back from the legislature. But it was still a wonderful effort.

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Let's see. The other point to this about it not being looked at as a Title V or a Department of Health, is that we take it off campus, we provide the structure for it but we certainly don't want people looking to us to solve the solutions. What we're doing is helping the community to solve them so.

HOLLY WILLIAMS: Got it? Okay, the other two things we wanted to touch on but I'm not going to go into great detail are the Utah Autism State Plan and anybody is welcome if you're dying to see either of these grants or the plans or any of the tools we're talking about, you're welcome to email me or Harper. The state plan covers these basic major objectives and under them, and this was done in preparation for the ASD grant that we wrote for it because you had to have that in place. The Autism State Plan covers all six of the national performance outcomes all the way from the screening clear to adult services and it includes actually a lot of adult services; health care, jobs, housing and things like that, so.

Our ASD State Implementation plan, there are four main strategies under the state grant. We're under the third of three years; we're just beginning the third year. First is the medical home training which includes about half a dozen, includes a lot of medical homes, traditional medical homes but also about a half a dozen dental homes in our second year which was kind of interesting. And then, of course, everybody I hope has heard about the medical home portal. We added modules to the medical home portal about autism and early diagnosis and screening tools. And then the early diagnosis, we also worked with the early intervention centers and

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we did some teachers education and then we've also worked with Jeannie Pulamoney and the Utah Parent Center. We have six trained family navigators. We have in each one of the medical homes, about 16 medical homes, we have the team with the family navigator person. And then finally we did a very interesting autism ABC's which is a CD that we put out. It's training for parents who have a newly diagnosed child with disabilities and there are 12 different modules that are an hour in half each, which is very long, but there's training the trainers and they are translating into Spanish and we're willing to share that I think; I'm pretty sure we will.

Finally, I was going to talk about quickly what leveraging we've done. We are continuing our clinics. That's something we've been a Title V agency that does clinics so we have had as everybody else bombarded with financial problems, we've worked very closely to develop a new module wherein the University of Utah will do their own billing and then we provide the surrounding services for the evaluations for children and it turns out we're evaluating about 20-30% of all the kids we're evaluating have autism diagnoses. And I think that's not because I think because they're all coming to us throughout the state. We're the only game in the town in the rural areas. And then the Medicaid Service Management previous known as Administrative Case Management, which we can't call it that anymore, that has helped us bring in and this year its working again, we're bringing in about \$1.5 million to our clinics to match. We have lost everything from about \$500,000 of state general fund and that has been reserved to

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match for the Service Management Activities that we get. And then Utah Regional LEND, I want to just mention that and I'm not going to go into detail. A lot of people have the LEND Programs. They had the autism supplement that's been helpful. And currently added on to our autism grant, we have the Learn Signs Act Early Public Awareness Campaign that we're working on.

So, and Barbara's going to wind it up.

Barbara: Well, as much as I would love to convince you that we developed a system in Utah, I don't think we have. I think what we did is we recognized the pieces of the puzzle. We identified them. We helped everyone else learn about them, and what our role really has been as Title V representatives, is providing the glue. A glue of communication and collaboration and eventually it might develop into an infrastructure but it isn't felt by us nor is it seen as our responsibility to create that infrastructure and I think that's why everyone keeps going to come toward the table to talk. So. Okay.