

2011 AMCHP and Family Voices National Conference: Merging Data and Policy for Children's Health: Influencing Change at the State Level Using the National Surveys of Children's Health and CSHCN

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

DR. DAVID ALEXANDER: A little out of order because we're a little bit behind time.

As my mother lives in an assisted living place up on Connecticut Avenue, she have had her come down in here this introduction I got this morning because I didn't know I'd done all that stuff. I just wanted to introduce you a little bit to the Lucille Packard Foundation for Children's Health and through that allow me to reintroduce Christy and some work that we commissioned, Christy and CAHMI to do.

The Lucille Packard for Children's Health first of all is not the David and Lucille Packard Foundation, our very wealthy neighbors down the street. We are a small spinoff of Lucille Packard Children's Hospital. We are an independent organization and we really do three things; although we are a affiliated with Packard Children's Hospital in Stanford, we are independent of them and the largest thing that we do actually is we're the contracted fundraisers for Child Health at Stanford. So we actually have an army of fundraisers to raise money for child health activities at Stanford.

That said, we have our own independent endowment, which was created when the foundation was started and we used that endowment to do two things. Number one it is our goal to be the go-to source for health information about children in California. And to put it in perspective, how many Californians are in the room here? Two. We've got probably 50 people in here and two Californians, so it starts to look like the US Senate instead of the House of Representatives because interestingly one out of every seven American children lives in California.

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So to put it in perspective when I moved out there having lived in Pennsylvania and Iowa and Michigan, the scale of things gets to be immense but clearly about 15 percent of American children live in California and we're a pretty representative state in terms of the diversity of America today. So we really are attempting at the foundation to be a source for health data **** in California. We do that through a website. CAHMI has a website called ChildHealthData.org. We being in California are a little less formal so we have KidsData.org. KidsData.org for those of you who have never looked at it contains what we believe to be every available, publically available piece of data about the health of children in California.

There are just under 10 million pieces of data in KidsData.org right now and if you've never been on it, I'd suggest you go on there and you can play with the data, you can generate charts, you can import data to your own websites. It's a very user-friendly thing.

The other thing that the foundation does, when I was recruited a few years ago, the board of the foundation asked me to look at our grant making program and we give away about \$3 million a year to support activities to improve the health of children in California and they asked me to look at developing a new focus area and where we landed is looking at the system of care for children with chronic illness in California. That's largely out of my observation, personally, and that of many other folks that we work with a world class children's hospital and if you as a child with a complex chronic illness show up at Packard Children's Hospital or at

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Oakland Children's Hospital or at Children's Memorial in Chicago or wherever you turn up, you tend to get fantastic care during that episode of illness when you're acutely sick and at the hospital, but for the 98 or 99 percent of the rest of your life when you're at home the community, the system doesn't work particularly well for you. And it probably works a little less well for you if you're poor and a little less well for you if you live far from an active **** center and a little less well for you if you don't speak English, but it doesn't work real well for anybody.

So the large portion of our foundation's grant making work is to try to build that system of care outside of the hospital. That's largely what we go and when we started on this work, we realized that there was a gap in data in California about dealing with special health care needs. That we had all of this richness of data on KidsData.org but when we tried to actually pull data from our website about how kids with special needs in California were doing we didn't know a whole heck of a lot. So we went to Christy and to CAHMI and asked her to take a deep dive into the publically available data about California's children with special health care needs and help us better understand how they were fairing and I'm going to let Christy come back up and talk about some of those findings but I will say that we now just gotten Christy's first report and if you go on our foundation's website which is LPFCH.org, among many other things you'll see an extensive report that Christy did analyzing the state of affairs for kids with special health care needs in California at least as reflected on the national surveys.

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We are out there promulgating that data. We've gotten a lot of media coverage and we're using this data quite frankly as the call to action to launch what we hope will be a statewide collaborative, which we're calling the California Collaborative for Children with Special Healthcare Needs **** advocate for public policy. And as you may or may not be aware, California has a little bit of a budget problem and among the many brilliant things that the legislature is in the process of thinking about to solve that budget problem right now are applying co-pays to children under Medicaid and limiting both doctor's office visit coverage and prescription coverage under Medicaid. So we're hoping to be able to use some of these data to inject some sense into this dialogue.

So let me introduce Christy.

CHRISTINA BETHELL: I just want to say how wonderful it is that this person, David, decided to take the risk to use the national data that the Bureau has put out and really torture it for what it can do for a state. And I got the job of trying to figure out –

DR. DAVID ALEXANDER And I'm going to get out of the way and let you talk about it.

CHRISTINA BETHELL: **** to his Board with all of the things that can go on when you start stratifying data by a state and trying to make policy sense. So we learned a lot and I really was excited about taking that deep dive because it was very consistent with the work of the data resource center and we were getting ready to begin work on a national – you're still telling me I'm not supposed to talk.