

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. CHRISTINA BETHELL: And what could you do is also combining data across the two big data sets to the National Survey of Children with Special Healthcare Needs and the National Survey of Children's Health, which we also haven't really ventured very far into, how might you tell a coherent story about children with special healthcare needs given that you can stratify everything in the NSCH for children with special healthcare needs? And what do you do when you see a slightly different things and people get confused an all of that. So it was a great opportunity.

So, I'm just going to go through and do the fun job of showing you what we've found. So, this is the picture of the report. It looks at describing the population, looking at system capacity, quality of care and the impact on families and children. Our goals were to create more understanding and commitment from what they already knew in California to offer some new insights for improving policy and practice and priorities and to motivate and inform the formulation of new ideas which the foundation has led a lot of the dialogue around.

Data and methods highlights. You probably know more than you want to know but we used, obviously, the data that the National Survey of Children's Health and the National survey of Children with Special Healthcare Needs, all standardized, I'm not going to say any more about that.

So we found about 14.5% of children, about one in seven children. So what we did in the presentation of this data is tried to make it more interpretable by a common person and often business leaders

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.

and other people who are in a position to influence policy need it that way and advocates as well, so that's how I'm going to present this. But it equals about 1.4 million children in California. If you took California and took a point that, it's 174 miles wide, how many miles wide are their publicly insured children with special healthcare needs? 49 miles. 111 for privately insured. Most of those miles still privately insured so wakeup private sector health plans, you need to care about this population. Uninsured: white and non-white. More non-white.

Other highlights: 73 miles of school buses filled with children with asthma. 103 miles of children filled who have two or more conditions. There are virtually no children who have only asthma. There are virtually no children who have only ADHD. We're talking about children with complex, multiple conditions and we only measure 16 of them on the national survey and that is a fraction of what conditions children have. If you want to talk about conditions specific approaches, you're going to run into a wall because you're not talking about children or any real children, anyway. I mean there are some reasons to do that.

Overweight or obese: 60 mile of school buses filled with children. Complex needs, those who experience functional difficulties because of their special healthcare need, most of those miles, 152. If you put it in further perspective, and you have the Staples center, which downtown Los Angeles, where I used to live, I actually lived in California for the first 25 years of my life, 30 Staples center filled with children with special healthcare needs. That's how many are in California. So there are 14.5% of the population,

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.

but you can fill 30 Staple centers with them. So often translating it like that can make it more salient. Twenty-nine Staple centers with two or more complex conditions, 20 for emotional/behavioral developmental issues and going all the way down to Down Syndrome. So you can see the point we're trying to make here.

Gaps in coverage, about one in nine, which isn't very many, but we do know that even if you do have coverage, about one in three experience coverage that is not adequate to meet their needs. Using a pretty low bar assessment of that actually, it's not very strict assessment.

Service use: High need for service. Forty-two percent have at least five types of service needs. And about two in five did not receive needed mental health care.

Highlights of national comparisons: California looks like it has fewer children with special healthcare needs, which is actually consistent with the higher rate of Latino population. There is both a lower prevalence, but once identified there tends to be higher functional limitations which is consistent with the literature for looking at conditions and health status issues for that population in general. So we didn't... we expected that. And in terms of the national comparison, I had no idea when we went into this where California ranked, honestly David, I thought I was going to be some good news. I mean, California is innovative and it's on the West Coast and it's sunny out there and so come on, you know, but actually it was pretty alarming and I really don't know until you look in and you start putting the story together across indicators

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.

and across children and looking at systems as a whole and children as a whole and you really get a different story.

So, California ranked 49th in the simple measure in the national survey of children with special healthcare needs on access and community-based services. And you can see here, basically, either the bottom or the bottom eight states on all of the outcomes measures in the CSHCN survey worst or second to last, I'm sorry, David, I hope this is okay. And also stress among parents. We talked, you know, Dr. Blum just spoke about stress being a you know, sort of one of the most underlying consistent issues that so many deal with it relate to some many illnesses and stress among parents of children of special needs was much higher in California and so on.

So there's a lot of information like this that came out with the report. Again, more functional difficulties, so the prevalence is lower, but then once you find those kids, their functional difficulties and complexity is greater. So in some ways, the density of the need is greater even though the number might be smaller and that has different implications for systems that doesn't necessarily translate into fewer services or even different services.

By insurance type: A lot of wide differences. I'm just going to flip through these quickly because we did start late, but we're still going to try to end on time. So privately insured children with special healthcare needs are more likely than publicly insured to receive all components of family-centered care. And why would that be? Family-centered care is measured in terms of human

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.

relationships. Why would the human relationships when you go get your healthcare be different? You can't really legislate that kind of thing, you can train for it, but you can't mandate it. It's not a service, it's an interaction and it's an interaction that really has a huge amount to do with all kinds of outcomes and adherence to medical advice and it goes on and on. So this is pretty interesting. That's the 26% difference and there's a lot of questions about what that's about.

So we can go through this, but these are the kinds of things you can do for your own state, it's a good model if anybody here is interested, we also have done something along these lines, much less extensive with few other sort of helping with other states through the data research center, but this is the most comprehensive example.

And then the impact on school and family. This is very important to know that the National Survey of Children's Health really allows you to look at neighborhoods, school, impact on family and other variables that are not as available in some of the other surveys. So, it's important to consider those areas and we translated this into about, families spend about 3,780,000 per week coordinating care, which is equal to about 94,500 employees and is three times the size of Humboldt County had to cut back or stop working because their child with a special healthcare need had issues that required them to be not working as much.

So that's a way to consider translating the data. So before we were talking about analyses and P values and everything else and here's

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.

another way to think about using the data in your state. And I'm not going to end with the last few slides because this was really for your board and recommendations. So hopefully you've been inspired and will go forth and do good things.