

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

02/12/2011 Omni Shoreham, Washington, D.C.

CHRISTINA BETHELL: Okay, great. So my job is to talk about how to make the most out of the national and state child surveys that Michael introduced to you and give you some tips for what I'm calling the Journey Through the Data Analysis Labyrinth. And so before I begin, I do want to acknowledge Dr. Kogan and his colleagues at the Maternal and Child Health Care Bureau for their leadership. Dr. Kogan, you actually direct the Office of Epidemiology and Policy and Evaluation, which is responsible for making sure that not only the surveys go through, but also the Data Resource Center. So I just want to make sure that you all know that and they're duly recognized in this.

And so let me take you through, I don't know if we needed to do this, but my goal is to inspire you to more extensively and effectively use this data. I think it's been used quite a lot and we have evidence that it has been, but I think you can be using it a lot more to inform and improve state policies and programs.

Second is to outline a very simple conceptual map that can help you just get your mind around thinking about how you might actually go about using the data to get the most out of it for your state. And also to build your confidence that you know you these things are doable and I don't know how many of you do... do analysis for a living, but if anybody's going to be out there making decisions and running programs, hopefully not everybody's in the back room doing analysis, but what we really need leaders who feel comfortable with both. Who feel comfortable at least with conceptualizing and thinking about what can be done with the data

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so that they can give direction to the team that they have to do that work. And if it's important for you to know enough about it and to be visionary about it because as I'm going to end today and tell you, I'll start at the beginning telling you this that I think it's really the people in the front lines and in the programs themselves that are going to have the most intuitive and instinctive sense about what all of this data might mean and what would be interesting to put together into what are the important questions, what are the different analyses that really can inform policies. So you're very critical.

So the first things, I found a heart-shaped labyrinth because it's Valentine's Day. And I'm sure you're going to be sick of hearing about Valentine's Day by the time today's over. But this is a labyrinth so the first encouragement I have is that I think there really is a natural progression through data analysis if you start going through it, it leads you. And so I think you're going to be led naturally through some of the questions I'm going to pose that the data can answer. But there's also a caution, which is when you go into a labyrinth you have to be able to get back out. And so you need to kind of go in with some kind of purpose and intention so that you really can come back out with something you could make a difference and interpret. And that's often a downfall of data analysis is that it looks all very interesting and we go in there and find all kinds of associations, but we don't end up coming out with something that we can actually act on, so I really want to continue encourage being intentional and being thoughtful before even entering in.

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So here's the labyrinth. There is the first step, which is my state. If you want to know, what is the prevalence in my state for the variety of topics that are covered in the national surveys? And what are the disparities across child subgroups in my state? That's where usually where you want to begin with my state. And just answering that in an effective way is very important and powerful. And then if you want to venture further into the labyrinth, you want to compare your state maybe to the states around you, to the nation, to all other states. Where does my state rank, is a question there. Is prevalence and are disparities in my state different from another state? Or, are children who are from certain socio-economic groups fairing the same all over the country or does it vary? And if so, why?

And then finally, if you want to kind of approach the center of the labyrinth you want to start getting into understanding the differences that you will see and you will note both within your state and across states. So here we want to know things like are the difference is significant? They look large, but you know, there's not always such large samples for some of these items when they get down to age groups or certain racial groups or something like that. So are they significant? Should I be speaking about them as if they are? What is associated with the differences within and across states? What makes up the differences? Are they all just about differences in demography across states or is there something else going on? Do the associations vary? The strength of being male in my state for an outcome, is it the same as in

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another state? And then can, obviously, the Holy Grail in the middle of the labyrinth is can they be explained by anything that we can do anything about? Policy and programs, and that's really where you want to end up hopefully.

So your first steps, I'm going to quickly go through the next few slides. Luckily you can get a lot of data for the first several steps of your journey from the Data Resource Center, so you can get what is the prevalence in my state from the Data Resource Center. And how many of you already know about the Data Resource Center and have gone to the website? Okay. So you can get any of the variables that are in either of the national surveys and any year of them by your state and you can also look at subgroups for your state and if there are subgroups that you don't see, you can search by, you let us know, we sort of do it on a demand basis adding stratifying variables that you can interactively search, but here is an example of by children with special healthcare needs and not for body mass index and being overweight or obese. And you can see that there is a difference so that right away can be interesting to you.

So then there's the first steps, analytic questions. And this is when you start to have to actually either get the data set are somehow convince somebody to give you standard errors and calculate a statistical test for you. So if you really want to know whether or not the difference between the two groups, and in this case I'm showing children with special healthcare needs and children without special healthcare needs who have adequate insurance and

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don't have adequate insurance. You need to actually run a statistical test because again, we're dealing with samples and we're dealing with samples with levels of precision and when you get down to subgroups sometimes the precision isn't is great because of samples. So you want to actually answer the question whether it's statistically significant, that's when you have to you know run the test and you get the data, if that's all you need is a couple of statistical tests, called the Data Resource Center, we often do quite a bit of this or we can hand you the standard errors. We actually have the standard errors in a file for all of the data that's on the Data Resource Center and routinely send it to people who want to fast-track and not have to download the entire data file and do all of the complex sampling adjustments that you need to do to get a valid standard error, for those of you who are not **** like there's something about that.

Okay, so the next... first steps, analytic question is, are child subgroups with a higher prevalence still more likely to experience an outcome after adjusting for other factors? And that's a really obvious question. You know, if you see differences between children who are publicly insured and children who are privately insured, I think it's a common thing to think, well it's just because they're poor. And there's all kinds of factors that we can't control as well about that, so is that all it's about? So that can be a very important policy question to answer is differences between sectors of children and insurance programs.

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So here is just an example of differences, for example in Medical Home, and this is done at the national level, but the analogy at the state for children who are privately insured and publicly insured, for children who meet sort of a minimum index of quality across a couple of variables in family centered care. Now those look like pretty interesting differences. So when you put into an analytic model adjustment for other factors like race and age and income and so on and so forth, do you still see a difference? And that's often a really powerful thing. If you're lucky enough to get a legislator to pay attention to you or a program leader to pay attention to you using this data, believe me, the next thing they're going to ask you what they think about more is, is it significant? That's interesting, you've got my attention. Is it significant or is it just about all these other things. So you kind of end up getting drawn in a little bit.

So you can see here that for this minimum quality Index in the middle, and I wish I had a pointer, if anyone has one I'd love to borrow it. We see about a 12 point difference between privately and publicly insured for a minimum quality Index. However, when we adjust for that with other variables, it's no longer significant. So you can say that, you know, in the nation, children who are publicly and privately insured are both really experiencing a lot of... okay thank you... a lot of similar issues. In different areas; but similar issues. And so they're not really all that different, so this isn't just a poor kid's problem. That could be an important thing to know about and you don't always know about that until you start doing adjustment. That requires what's called

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regression modeling. Most often logistic regression because most often this data is put into, "yes", "no", has it, doesn't have it. That's not always the case, but for the most part it is.

So another first step analytic question is, are my states over all prevalence and child subgroups prevalence rates different across years? And Ashley is going to talk more about that. There are now a couple of years of the NSCH data and we're coming on three years, three different versions of the National Survey of Children with Special Healthcare Needs, so this issue of looking across time is becoming more and more relevant for these surveys and more and more exciting. So stay tuned for that.

And to do this, well I wouldn't actually give you an example here; this is for children overweight and obese. You can see that it didn't change in the two years for overweight, but actually that's a significant difference in obesity. So taking it apart across time can be important to understand, well maybe our programs are impacting risk more than they're actually impacting people who are further down the continuum of illness or other problems. So that's just an example of why you'd want to do that. And then you can do it for subgroups of course so whatever you do at the state level you're going to want to probably repeat it at subgroups and you're going to run into some sampling issues, which is why you ought to buy some more sample for all the new national surveys, which states are allowed to do. I highly recommend it.

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Okay so if you venture further, that's the second stage where you want to start comparing, how does the prevalence of my state compared to other states and the nation as a whole. You can also start doing that on the Data Resource Centers so you don't have to go to in a getting the data and doing all that. You can find out how Mississippi, for example, compares to California, I picked that just for you David, in BMI status. And it looks like there's, you know, 14% difference or so. That's not small.

And then if you want to know where your state ranks among all states, you can also do that on the Data Resource Center and go in and look at the all states feature and pick a variable and, you know, you can click on it and it will rank your state... the states up and down from highest to lowest or lowest highest. And then you can also stratify that by variables. For example, this is stratifying for whether children have also have an emotional or behavioral or developmental issue. So you'll see that Illinois has the highest overweight/obesity rate for children who have emotional, behavioral or developmental problems. Now they didn't even show up at all in the ranking, it was Mississippi that was the highest, but actually for kids with these problems, it's Illinois. So you just can't assume, you have to really look. And you find a lot when you do that. And this you can find on the Data Resource Center.

So another step in the journey is to ask, how do disparities in my state compared to disparities in other states? So now you get into the disparities of the disparities. And actually when you get into

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some kind of modeling isn't it disparities of the disparities of the disparities ***** modeling? There is variation in variation and then there is variation in variation of the variation and so that can be fun. But this is just, are there differences? So here we see that Minnesota actually in the country has the lowest rate of overweight or obesity, tied with Utah, about 23.1%. And Idaho is, you know, probably around 27%, as you can tell there. But when you actually go into Minnesota and stratify by insurance type, you find that the rate of overweight and obesity is very high in Minnesota. So obviously there's not a lot of children who are publicly insured from account level, at a population level who are publicly insured, otherwise it would have skewed the state rate more.

So you have to kind of dig. So they have actually the highest disparity for public versus private insurance. Idaho has virtually none. Why? So if you keep going, you see that everywhere pretty much. So it's not the same to be privately insured or publicly insured in one state as it is in another. And that's interesting.

Another analytic question. These are all separate questions. They all sound kind of the same, but they're all different and they take different approaches. Does the prevalence in my state differ significantly from either the nation as a whole or another state? You can get maps on the Data Resource Center that answer the question of is my state different than the nation? But if you want to start doing that and answering that question at a subgroup level or state by state, you actually need to get the data and it requires what's called nested t-tests, which is a certain kind of test and also

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adjusted for the complex sampling. However, if you just want to map and you can see how your state compares on some of the key variables, you can get that from the Data Resource Center. I encourage you to do that.

So analytic questions when venturing further, our variations across my state... are variations across state statistically significant? So you'll see again a lot of variation, highest state for overweight/obese, low, developmental screening varies quite a bit, and keep in mind this is standardized data. So even if you don't think that it was measured perfectly, it's measured the same. So you can compare. So you know, I think that's a really important point. If we're both driving up the... riding our bikes up the hill and were faced with the same wind, at least we can still compare how fast we were going even though both of us had a bias or something or somehow impaired from going as fast as we might. So participating in activities, California, Minnesota, repeating a grade is pretty wide, and it's even wider a margin if you have a special healthcare need, so 25.4% of children in Louisiana and Utah.

How my doing on time, by the way? Okay, I think I'm okay. Alright so the simple thing to... I need about five more minutes. Okay, I need about five more minutes now.

So the simple thing to do is just test it, but don't you really want to know if the effect of child level demographic and other health factors are really what is explaining these differences across states?

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Don't you kind of really want to know that and what those effects are for your state? And even better, whether associations with these demographic and other factors are the same? For example, the impact of having a special healthcare need or poverty or insurance type, is it the same or different across states and we had some illustrations up until now.

And even more ideally, whether any variation remains after you've adjusted for all of those demographic factors. Is there anything for policy to do? Perhaps. Or is it really just the luck of the draw and the children that live in the state and their natural propensity toward illness. You know, some people would argue for that.

And finally, whether any across state variation that remains can be explained by policy. So that's really where you end up in this natural progression if you keep going is you want to understand the differences. And that's where you can get into things like multilevel modeling. I'm just going to just take a few minutes to explain an example and then I will end.

So how many of you have heard of multilevel modeling? Okay, so it's really a very simple explanation. It looks at variation at two levels, both the individual level and then in this case we're going to be looking at the state level. Estimating the association between child level factors and an outcome of interest, let's say whether they have a Medical Home or repeated a grade school. Allowing those associations to vary across states as we've seen that they do. So if you didn't do this, you would be able to capture that

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information. And for those of you who do analysis, you know variation is information. So we'd lose all of that variation without doing this kind of modeling. It assesses the significance of any of across state differences in the associations that we are observing on whether having a certain type of insurance are having a special healthcare need impacts a certain outcome like repeating a grade. It tells you how much variation remains after accounting for the variables that you include at level I. Is there a state of fact?

So level II would be examining the state level variable, contextual variables is what they're called. And whether it has a large, small or no effect relative to the variation that's not explained at level I. That is hard to talk about in a couple minutes so I'm not going to try to, but that's what it is.

So here's some examples, school nutrition policies, payment levels for developmental screening might have an impact, eligibility rules for early intervention, violence education and tolerance policies in schools, public insurance benefits standards, case management for children with special healthcare needs in school. And that's the example that I'm going to give you.

So here's the background on the state policy variable. In 2006, 26 states had a policy requiring the provision of case management for children with disabilities commuted. Obvious questions are what's case management? How do you decide who needs it? Who decides if they get it? Putting that aside, the average rate of grade repetition for children with special healthcare needs in states with

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case management policy was 15.7 and it was higher for states that didn't. That was quite significant. That's interesting. Obvious question is, is that because there's just differences in those states that are more advantaged or disadvantaged in some other way?

So the example is, you know, what we're finding is... I did think I had 20 minutes, did I not, I'm a little nervous about that. But I'm going to keep going anyway.

So if you look at children with special healthcare needs, you want to look at them by their complexity and the type of conditions they have sometimes because I can be very different. We do want the broad definition but we also want to look within that. So there's children of less complex needs and more, children with emotional behavioral problems, children without, and they are distributed in this way, about 40% have less complex and no emotional behavioral, and about 40% have more complex and do have emotional behavioral problems. And we can see grade repetition is significantly and way higher for the children who have more complex needs and emotional/behavioral problems.

And so when you do regression you always pick a group to compare to, and in this case it's the less complex group with no problems. And so you have, using multilevel modeling the equivalent of an odds ratio of 3.16, for the second group to 2.25 and 4.96 and then it answers the question, which is a fabulous question, does that affect vary across states? And the answer is, yes it does.

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So if you interpret it, it would say children with special healthcare needs with more complex needs and you also have an emotional and behavioral and developmental problem which is about 40% of all children with special healthcare needs fall in this category. On average across states have nearly five times the odds of having repeated a grade in school, the effect of having more complex needs and an emotional, behavioral, developmental problem varies significantly across states. If similar children with special healthcare needs moved from the state with the lowest to the highest prevalence of grade repetition, they would still have yet greater odds of repeating a grade even after adjusting for all of those characteristics including their complexity and type of health condition. After adjusting for these other variables, age, sex, race, income and so on and so forth. So that's kind of the example.

And at the level II, I've never gotten a level II significant policy effect because there's really hard, it's hard to find good variables. But we actually did see an effect of whether there was case management policy for disability in schools on top of all of the level one factors there is a effect of living in the state are being in a state that has a case management policy in schools for children with disabilities that being yet again, less likely to have repeated a grade in school.

So that's just one example. And there are many more, you can stay tuned for lots of other pieces of information, for example, violence prevention and prohibition policies, what impact do they have on

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children with special healthcare needs participation, engagement. And before you venture in, I just want to say that state policy variables are hard to find, you need to do a lot of work to get a conglomerate of them together that also are very relevant to the national surveys if you want to make the best use of this, and you have ideas, I'd love to hear it. That even if you don't find one, running a multilevel model still is very powerful even if all you do is run the level I. And don't begin unless you are prepared. There is plenty to do without having to run these kinds of models. And then also don't lose sight of the big picture.

I've said before, that even though, you know, children who are publicly insured may be more likely to have risks, the truth is, is that most children, for example in the country who are overweight and obese, are privately insured and do live in a neighborhood with a park and are living in households with higher incomes. So most of the kids are not disadvantaged who are experiencing these poor outcomes even though those who are disadvantaged are more likely to.

And that a significant state-level effect may be small and really not be where to put your money, on the other hand, it may be very small and small effects can lead to large changes. So you have to really think about what does it mean.

And this is from Adam Carl, this is part two. At the end of his MLM presentation and since it's Valentine's Day, I'm going to end again was saying, to follow your heart. As what I mean by that is

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you have an accumulated set of experiences and insights that really should be the starting point for any analytic process.