

AMCHP 2008 ANNUAL CONFERENCE

WE ARE MAKING A DIFFERENCE:

Using Mapping Software to Identify Barriers to Special Medical Services

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KATHARINE HARRIS: New technologies to develop. New conditions. Testing for new conditions. Or even the old conditions that are better screeners. You might--you may be familiar that sickle cell disease when we--when newborn screening program screen for sickle cell disease, it's actually a diagnostic procedure. All of those children, assuming the spot belong to that child, that child has what we said, in terms of sickle cell disease. All the others are just screening tests and phenylalanine is pretty specific, but we do find that kids might screen high or relatively high for phenylalanine and not be diagnosed with PKU. But even more, congenital hypothyroid is just a dirty, dirty screen. The thyroid is so traumatized or the pituitary gland, which is--process a lot of it. It's traumatized by birth or early, the kids who were born early, their pituitary, their thyroid is not working well. So, if we get them right at 24 hours after birth. If they are preemies, their thyroids aren't going. So, hopefully we collect one a week later, and then suddenly they got--they may have hypothyroid. But we have a huge number for congenital hypothyroid that screened positive, diagnosed negative. There were, they call them false positive, which is not really true. They screen positive. We get really defensive. These are screen positives, they're just not--because we're

using a pre-generalizable. And now, with the (inaudible) after looking at all these carnitines, C zero, C3, C5, CDC 3, I don't even know what they are. But the screen positives are killing the metabolic centers because, when they, they don't really know what to do with a lot of cases.

UNKNOWN SPEAKER: I know the big issue was new born screening...

KATHARINE HARRIS: Yeah.

UNKNOWN SPEAKER: ...hasn't change about (inaudible) with follow up and really that often in follow up, so you identify these kids...

KATHARINE HARRIS: um huh

UNKNOWN SPEAKER: ...and know that, you...

KATHARINE HARRIS: Yep.

UNKNOWN SPEAKER: ...know that...

KATHARINE HARRIS: Yep.

UNKNOWN SPEAKER: (inaudible) with your mapping...

KATHARINE HARRIS: Mm-hmm.

UNKNOWN SPEAKER...software that (inaudible) treatment?

KATHARINE HARRIS: Yeah.

UNKNOWN SPEAKER: You know, because I can see, okay, so here's, you have these cases and here's where your treatment center is in helping to identify that...

KATHARINE HARRIS: Yeah.

UNKNOWN SPEAKER: There are several issue for answering them versus, you know, we were concern about, not just screening.

KATHARINE HARRIS: Mm-hmm.

UNKNOWN SPEAKER: It's not only that. You know don't always (inaudible)

KATHARINE HARRIS: Oh, yeah.

UNKNOWN SPEAKER: How to, you know, how to (inaudible).

KATHARINE HARRIS: Yeah.

UNKNOWN SPEAKER: (Inaudible) video. Is there anything you can repeat, just that you're offline.

KATHARINE HARRIS: I'm sorry.

UNKNOWN SPEAKER: That you need to repeat.

KATHARINE HARRIS: Yeah. Well, just the issues that, it's easy to screen, you can screen for anything. But then, how do you follow up and how do you make sure that those kids get into care? And almost, note there are very few states and systems that know these kids stay and care over any long time. Most of the states, because it's just overwhelming to try to follow this kids, almost all the states follow them to diagnose, they are all states found the diagnosis and then trust that the treatment center is going to take responsibility for those kids from then on. But, you know, in our mobile society, or even insurance, suddenly your employer, if you're lucky enough to have an employer who provides insurance, changes providers in November and you have...

UNKNOWN SPEAKER: Change jobs.

KATHARINE HARRIS: You change jobs, you've moved. Yeah, so that, though, with specialty, specialty care centers, especially with the metabolics, there are so few of them that, they're going to have to. They're going to have to participate in almost all the insurance companies, the insurance programs. But then of course then, employers decide what's covered under the insurance policy. So maybe, you go so far. We have a huge problem with most of the metabolic diseases are controlled by diet, a formula, or a diet or supplement. And then you might need some medical supplies. The (inaudible) Secretary's advisory council is looking at how much of this is out of pocket? How much is insurance covering for these diets? And this can be expensive, the formulas, and you don't outgrow this. A kid with PKU needs to stay in formula forever. It was thought when they first started that that after five years, the brains develop. You can go off diet. And then about 10 years, 15 years later, we started, had developed this new condition that didn't exist hardly, maternal PKU. Women who got pregnant with out of control phenylalanine had very bad babies. This is a huge congenital condition, so say with high phenylalanine in the in the fetus. So, we had to go back and find these kids, these women and we put them on diet and they said, "My god, I feel so much better." Even though the brains weren't developing with this excess of phenylalanine, they were feeling really dopey and stupid. So, they--putting them on diet, they finally felt so much better. So, the mandate now is to keep everybody on diet as long as possible, forever. And as long as you can tolerate it.

So, yeah, long term follow up is a huge thing, both to make sure they'd stay in treatment but also to make sure if something new comes along, you know where these kids are for a new, there may be a clinical trial, there may be--there's a brand new, Kuvan is a new treatment for PKU. And it just had a clinical trials and it's amazing. It is not for the classical PKU. It relies on some residual enzyme activity, but it boosts the effectiveness of that enzyme activity. So, these kids are don't--not necessarily classical PKU, but some of these other PKU, phenylketonurias are just finding if their phenylalanine is normalizing. They can—now, they're trying to push them and see if they can eat food instead of drinking these diets or making these special recipes all the time. That's pretty, can be pretty nasty. But it's the only thing we'd been able come up with. So, I don't know how else we could--love your thoughts on how else can we use this mapping software to identify and then how can we reach out to these families who need this service from when they're--I don't know why they don't move closer. It would make life easier.

UNKNOWN SPEAKER: I mean, (inaudible) some of those kind of really helping facilitate (inaudible) areas and access to treatment.

KATHARINE HARRIS: Mm-hmm.

UNKNOWN SPEAKER: I mean, specialists, so they don't have to drive...

KATHARINE HARRIS: Mm-hmm.

UNKNOWN SPEAKER: ...120 miles and never...

KATHARINE HARRIS: Yep, sure.

UNKNOWN SPEAKER: ...driving and cuts Pennsylvania on the route. That was a really good place to use this and maybe kind of (inaudible). You know, (inaudible).

KATHARINE HARRIS: Yeah.

UNKNOWN SPEAKER: ...is really a good solution.

KATHARINE HARRIS: Oh, yeah, good question.

UNKNOWN SPEAKER: The video conference, things like that. I know that some of the rural areas in Pennsylvania, I mean, even have the technology to be able to do a video conference to some of these community health centers or more people accessing...

KATHARINE HARRIS: Mm-hmm, mm-hmm. The rural health initiative has been amazing.

UNKNOWN SPEAKER: Has been amazing. And it's really, really helped.

KATHARINE HARRIS: Yeah, apparently. And we just genetics—newborn screening and genetics programs have to learn how, where these things and tap into them. Yeah, we're hoping to do some of that. But, you know, I was talking about stroke program that New York City put in were all stroke. After a year out, they had been—they had used it four times. That's all the--that's like...

UNKNOWN SPEAKER: (Inaudible) educating the people.

KATHARINE HARRIS: They did massive education. They were, they went all over the state, they brought everybody in. They told them about what they were doing, what they could get by, you know, that they could now build for, that they could use this. And it's not that there was--the people I'm sure with stroke weren't on Medicaid. They were adults, so maybe not as much some of the kids but they were so disappointed that it really hadn't taken off. One of the new—one of the neat things is home health care. They're using this distance tragedy on and it doesn't even have to be rural. It's just like somebody who lives in the suburbs over there and they might be on a diabetes medicine or hypertension medicine and they can, you know, stick their arm in a cuff and that number can be sent over the air to the hospitals.

So, the doctor can monitor their hypertension, like on a daily or whatever, stick their finger in and have blood taken, you know, stick and have that analyzed on-site with the result sent. So, that kind of a distance strategy. Some of the things we were looking at, we're looking at the rural, the big picture. But we know that this is an issue even in cities. You know, some, I always find it interesting that a lot of these medical centers which were built 100, 150 years ago are not in nice neighborhoods anymore. You know, everybody's moved out. So, it's in, or you got a population here that is afraid to cross this population to get to this center here. So, it's not just long distances, it can be very, very hard. And then, look at the cities, if you have a child who's fairly disabled, plus you got another youngster, the mom's got to transport this one kid who's multiply disabled plus a normal crazy kid on a bus. That doesn't work. So, you know, they have--they put a lot of neighborhood health clinics and (inaudible) has funded a number of these outreach initiatives at the neighborhood health clinics to--so you don't have to go to Brooklyn Hospital, you can stay in wherever your—where your neighborhood clinic is, which is maybe just around the block and all you have to do is put the disabled child and a carriage and put the other one on a leash, drag them along. But access is amazing. I mean, I don't go the doctors because I just don't like to. And so, there's (inaudible) I don't have this all these issues but...

UNKNOWN SPEAKER: For those kids with undiagnosed conditions, I mean, the other problem is care formation, like, I have a nephew who has a (inaudible) and he has multiple, his leg specialist...

KATHARINE HARRIS: Uh-huh.

UNKNOWN SPEAKER: But they don't talk to each other and my sister has to learn how to talk to them (inaudible) them what each other said to her and she's like, I'm not a doctor. I don't know how to interpret this. That's another element of that. What about the kids that don't have—the undiagnosed.

KATHARINE HARRIS: Yep.

UNKNOWN SPEAKER: You know, don't have a diagnosed condition, is how do you train those parents to, you know, serve in that capacity to be the advocates for their kid and also to, you know, do that care formation that should be happening.

KATHARINE HARRIS: Yep, care coordination is...

UNKNOWN SPEAKER: ...transferred and...

KATHARINE HARRIS: Yep, care coordination. And they talk--this thing about medical home. I mean, it's supposed to be the be all that end all. And yet, and whether they have a diagnosis or not, kids with multiple problems, one of our wonderful, Jenna Monico, her son has isovaleric acidemia and did not, it was

pre-newborn screening. She now has a child post-newborn screening who has the same condition. It's just normal, but Steven is just on ventilators and has so many specialists. And for her, for somebody to tell her, you need a medical home. Your primary provider should be a medical home. She just looks at them like they're crazy because she's the medical home.

UNKNOWN SPEAKER: Right, a lot of parents...

KATHARINE HARRIS: Because she's the only one who knows whatever—yeah, they don't have the medical expertise to know what it all means, but they know which appointment do you need now, you know, and they can transport the records. The system is not friendly for parents with this kind of issues. I mean, and it's interesting, we have what we call a health system but it's really a sick system. And yet, for kids who are sick, it still doesn't work. So, we don't have a health system, we don't really a sick system. We just (have mess, but that's another issue anyway. So, but anything else? No? You know, you're welcome to play with this or take it, go back and, you know, go. I mean, work. And it's that simple. It's up there on the web. But I don't think these systems are that expensive for, like, a health department or something to sort of gather the data.

UNKNOWN SPEAKER: It's not so much the expenses, the person...

KATHARINE HARRIS: Yeah.

UNKNOWN SPEAKER: Doing the data entry?

KATHARINE HARRIS: Yep.

UNKNOWN SPEAKER: Yes, data of entry. You know, the...

KATHARINE HARRIS: Yep.

UNKNOWN SPEAKER: Yeah.

UNKNOWN SPEAKER: And, you know, just the expertise on the software.

KATHARINE HARRIS: Oh, yeah.

UNKNOWN SPEAKER: It's not the hardware or the software issue.

KATHARINE HARRIS: No, you're right. You're right. It really is the skills and getting the somebody dedicated to look at that. Yeah, and finding the money to plan to make and do that.

UNKNOWN SPEAKER: (Inaudible) the data of its, you know, the data sharing of hospitals...

KATHARINE HARRIS: Data sharing as a big deal though. I was, I must say NYMAC has had a wonderful experience with, especially with our newborn screening programs. They're right, they've been signed up with us from day one and they'll give us whatever we ask for. I just, I'm so impressed and pleased, especially care centers in general are very, very responsive. We're having a lot of trouble getting with the AAP, AAFP. Sometimes we'll find a champion within one of those. We've got a pretty good person in NYMAC in Virginia who is part of that region three or something, whatever it is. And region two, we have pretty good people that, I think that's Delaware, Pennsylvania, Maryland, maybe that D.C.. Virginia is its own, New York is its own. We're having a terrible time getting, making an inroad in New York chapter. They're not returning our calls and, you know, though we had this champion in New York, in New York State. In Medicaid, he's the medical director, but he started out in one of our health systems, in our Capital District Physicians Health Plan. He was the physician there. He's an endocrinologist, anybody likes to do this administrative stuff and he was with CDPHP until they went to more administration than medical. Capital District Physicians Health Plan, that's what he was there for. Physicians designing what patients need and how to get it to them and using the medical needs as opposed to the financial needs. It's gone the other way. So now, he's a medical director for New York State Medicaid and one of the delightful things about Jim (inaudible) is he doesn't know I can do this stuff.

So, he does it. I mean, we work, given the mandate to put Krabbe disease up. And if you identify a child with new born infantile Krabbe disease, the only treatment is a bone marrow transplant. And right now, the only place that does them is Duke and you have to do this crazy enzyme test that's the secondary to reflexive screened it, confirm it and all this neurological work-ups and Jim said, okay, we'll cover it. I mean, that's pretty, we don't have too many of them we've had two, I think, that have gone to transplant in the almost two years that we've been doing this, a year and a half maybe up to two and a half, time flies. But Medicaid is covering that. But then they don't cover other things that (inaudible) stuff or the core conditions. We're having, our metabolic specialists are having a terrible time getting all the reflex tests that they think they need. We send them a screen positive for SCAD or MCAD or one of this crazy diseases that is only a chemical, as far as we know, and they can't get the labs to—they can't find the labs who will take the specimens for whatever they can get for them or nothing. Medicaid won't pay enough for the labs to sign up to do the testing. So, it's a big problem because they can't even work them up right. Anyway, but at least I think we know the issues. And hers has been pretty good about. I think their secretaries committee is really looking at the issues and trying to come up with some solutions or some pilots and stuff. So, it's pretty cool. Well, good. Well, thank you.

UNKNOWN SPEAKER: Thank you.

KATHARINE HARRIS: I'm glad I got here. You're here. Yeah, my pleasure.

UNKNOWN SPEAKER: (Inaudible) coordinator will come around and get your PowerPoint.

KATHARINE HARRIS: Okay.

UNKNOWN SPEAKER: And it has to be coordinate...