

## **HRSA/MCHB 2007 FEDERAL/STATE PARTNERSHIP MEETING**

### **Building Blocks for Promising Practice Models**

October 14 - 17, 2007

#### **Deficit Reduction Family Style: Understanding the DRA, the FOA and the \$\$\$ for Families**

DEBORAH ALLEN: Hi. Just one comment on the last discussion, is I think that some of what's going to happen around EPSDT versus the benchmark programs is going to be kind of triaging by difficulty. That is, that I mean it's not just families who don't fully understand EPSDT but I think even more importantly providers who get disciplined by their experience of getting things rejected by plans and therefore stop prescribing them or promoting them for families.

So I think it's going to have an indirect or a de facto effect. It's lovely to be here and thank you all for turning out for this potentially dry subject on the next to last afternoon of the conference.

I think you will find that in a time where good news is hard to come by, there is some good news in the Family Opportunity Act. The next question for me is if I can figure out what the -- no.

I'm the co-principal investigator, as Linda said, from the Catalyst Center, which is the MCHB funded National Center on Children with Special Healthcare Needs. And we have taken the approach in our role as national center of developing -- we've tried to be both responsive to state needs and also to develop a kind of agenda that we feel focuses on key innovations that states can undertake to push forward an agenda around financing of care for children with special healthcare needs. And I want to just briefly mention what those four things are because I think they're all relevant. And then I will talk about the FOA in particular.

The first is that we think it's very important for states to begin to document using data in the National Survey for Children with Special Healthcare Needs and any other data available in the state. The extent of hardship among families in your states.

And I will talk about that more so hold onto that idea. Second is having made that case, issues -- opportunities that we would like to EMS are first maximizing coverage for kids

with special healthcare needs and the FOA as an opportunity to do that. Second, addressing the many, many costs families experience that coverage won't address, that go beyond what's usually covered by reimbursement. And one particular model that we've tried to promote is a flexible fixed spending fund at the state level. At present Michigan has one, New Jersey has one, Massachusetts has one, very flexible, very large amounts of money available as a kind of catastrophic illness fund. And we can teach people more about that if there's interest.

And then the final one is to think about strategies for promoting sort of how do you pay for the infrastructure, aside from what families need on an individual basis, how do you finance the infrastructure for children with special healthcare needs. And there our understanding from talking to states is the biggest unmet need is financing for care coordination. So that's our focus.

The kind of keystone of our work with states has been the publication of a chart book. And I won't talk more about that now. If you are not coming to the round tables and have not got one, you're welcome to pick one up at the end of the session. So now to FOA.

One of the things that I think is commonly experienced when you start talking about financing of care for kids with special healthcare needs, I have found this in my own state. I've heard it from people in other states, is a pretty widespread belief among policy makers that those kids needs are already being taken care of.

And they might point to state investment in early intervention, if the state has an expansive early intervention they will certainly point to any investment they make in Title V. They will absolutely point to IDEA, which everyone is sort of acutely aware of as a public policy question in states.

They will talk to what the state investment in Medicaid and the extent to which children with special healthcare needs may dominate Medicaid costs among children. Obviously much smaller than Medicaid costs among older populations and they will talk about both Medicaid waivers that may target specific groups of kids with special healthcare needs and SSI.

So there is this common sense that I've encountered and maybe some of you have among policy makers that the needs of families of kids with special healthcare needs, yes, life is hard in an emotional sense and there may be some logistical challenges, but

we have taken care as a society of the financial burden of raising a child with special healthcare needs.

Well, as I'm sure people in the room know, but I don't think we've done a very good job of clarifying this, that's not really quite the case. It is the case, and the National Survey on Children with Special Healthcare Needs tells us this, that very few kids with special healthcare needs have no insurance at all.

Most, if low income, are covered by Medicaid. Obviously more are covered by Medicaid proportionally than other children because of the ability to get on the Medicaid with SSI and also of course because if eligible families of kids with disabilities are more likely to take advantage of the option to be on Medicaid.

We also know that the SCHIP population includes more kids with special healthcare needs proportionately than private insurance. So low income families are finding their way generally speaking to the options available to them for coverage. Not entirely, but largely. And then we know most kids with special healthcare needs like most of the population in general of children are covered by their family's private insurance.

Then of course, in some states specific groups of kids, particularly kids at the sort of the medical high end who would otherwise need hospital or institutional level care may be covered by state Medicaid waivers. So coverage per se is not a major issue for kids with special healthcare needs in general.

And, yet, when you look at data from the National Survey for Children with Special Healthcare Needs, what you find is that 20% of families overall and close to a third of families at low income levels experience hardship which families expressly link to the process of raising a child with special healthcare needs.

So although covered, families are telling us that in fact they experience some hardship and that hardship is related to the family's income. One thing that's interesting that isn't on the slide is if you ask families whether they spend a thousand dollars or how much they spend on children with special healthcare needs, sort of inversely what you find in relation to this slide is that families at higher income spend more, which is probably not surprising, right? They have it to spend so they spend it.

And partly that may be because at the lower end, the poorest families have Medicaid and it covers more; but it also probably has to do with families having it to spend. Hold that

thought because I want to come back to what that means for children. That families at all ends of the spectrum are experiencing hardship. Families at the higher end spend more, but families at the lower end experience more hardship.

We also learned from the National Survey of Children with Special Healthcare Needs, and this obviously links to some of that hardship, that about a third of families nationally have to give up or reduce work to take care of kids with special healthcare needs. Which I personally think is an astounding figure, in terms of sort of capturing the amount, the extent of challenge involved in organizing the services that children need.

From a survey that some of you may be less familiar with, the National Longitudinal Survey of Youth, which hasn't been used widely to look at children with special healthcare needs, we can look across generations at families who do and do not have kids with disabilities, not defined quite like the National Survey of Children With Special Healthcare Needs but close enough. And we learn that mothers of kids with special healthcare needs who are working earn less than other mothers on a per hour, per week, per month, per year basis.

But what's really overwhelming from the National Longitudinal Survey Of Youth is that cumulative over the lifetime of raising a child with special healthcare needs families of kids with disabilities acquire \$36,000 less in assets on average than other families. Which I think speaks to the sort of multiple consequences of having children with special healthcare needs, that the hardship goes beyond simply the fact of earning a little bit less per hour and we will talk more about what causes that.

So what are the consequences when families are as these data suggest the payor of last resort. First, there's been a lot of attention to medical debt and its impact on family bankruptcy over the last few years; not mostly focused on children with special healthcare needs, mostly on adults who themselves have high medical expenses. But certainly some of that literature points to families, some percent of those families who have been bankrupted by medical debt, having children with special healthcare needs.

And in those studies people have self-defined what's medical debt and that may be too narrow a term to think about the expenses that families encounter.

The second thing I'd point to and here's where that difference between better off and poorer families I think comes in, is that we have to assume that richer families or better

off families, because they're by no means rich are buying things for their kid that other families can't afford to buy. Now some of that may be frivolous or not sort of not critical, but some of it may be better quality care. Some of it may be a little bit more ABA for a child with autism, for example.

And I think the notion that because of Medicaid we have a kind of equal playing field in terms of the quality of care available to children with special healthcare needs across income, there's some further examination, because it would be interesting to know if rich families are spending more, what are they spending it on and they're associating it with taking care of children with special healthcare needs.

Third, clearly other family -- if you have a family with \$36,000 less in assets on average, the entire family is being affected. Another child is not going to school to the college of their choice, the family is not going on vacation, someone is not going back to the parent for an advanced degree that would allow them to promote their career. There's no way to absorb that level of difference without it affecting your life.

Then the final thing we know both from the National Longitudinal Survey of Youth and implicitly from the National CSHCN survey is that the family may breakup. The National

CSHCN survey doesn't ask did your family break up, but it does offer us insight into how many children live in one-parent families; and from a query to the people who oversee the on-line data system, we learned that a higher percentage of families of kids with special healthcare needs report that the child lives in a one-parent family that is typical across the population.

So that may be an indicator of family stress, and some of that is undoubtedly due to the financial and related hardships. Pathways to hardship, we think there are sort of three ways of thinking about this and it's useful to keep this framework in mind.

First is that there are high expenses families have that are unique to having a child with special healthcare needs. So if your insurance plan has a cap on durable medical equipment. If you're in a bench marked plan and you can afford it, you may go buy that extra piece of durable medical equipment that other families they don't have a clue that anybody pays for that out of pocket.

They have no idea that somebody's paying for diapers or for a visit to an out-of-state doctor who happens to be the best in the world to deal with your child's condition when there's nobody in your own state that you feel is really competent.

So the first category I think you can think about is what do families pay for that other families simply don't have to.

Second is, higher expenses, and this may be even more subtle. Higher expenses for things every family has to pay for. So you have a kid with significant orthopedic needs, you rely on your mother-in-law to help you with care of that child. So you have to live in a neighborhood near your mother-in-law. Well you can't afford that neighborhood but you don't have any choice because that's where your supports are. Or your child has autism and destroys the furniture so you replace the furniture periodically, which nobody else has to do. Or your child is on, has some problem that is associated with malabsorption, so you don't, they don't quite need food supplements or medically designed foods but they need to eat a more expensive diet than other children do.

And all of that adds up. So that it becomes a part of the family expenditure. And then finally the loss of employment income that was pointed to in the National CSHCN survey. So for all of those reasons, the opportunity to take advantage of something that will reduce family hardship becomes a very important question, and I think it's important to see it as both a way of addressing each one of those potential consequences of family

hardship. The loss of services, the issue of family breakup, the loss of opportunity to other family members because of the cost of caring for the child with disabilities.

And the Deficit Reduction Act in the component that really was taken from legislation that Family Voices had been fighting for years the Family Opportunity Act, that was sort of plumped into the Deficit Reduction Act. But that piece of stand alone legislation or what could be stand alone legislation is a real opportunity to address those concerns.

What it does is offers states the opportunity to let families buy into Medicaid, possibly on a sliding fee scale. That's somewhat at state discretion or the amounts that they can charge families are prescribed in the law.

For children who basically meet SSI level of disability. So it's an opportunity to expand Medicaid the most expansive coverage because of EPSDT to a set of families in some states who otherwise would not have access to that coverage.

Question: Is this a real opportunity? Does this really change things? How will it improve things? Well, for families, again, better access to healthcare. Opportunity to alleviate the

consequences of uninsurance. Many people confuse the FOA option with state waivers and wonder why you'd go after one if you already have the other or could have the other.

Well, the answer is that the FOA option is not limited to kids at the very high end as the Medicaid, the Katie Beckett waivers are, nor is it categorical like many other state waivers. And it isn't capped. It doesn't require, it's not as prescriptive. So although it's prescriptive in terms of what the Feds will pay for around income, it's very open in terms of eligibility potentially for children.

And it offers families the option of getting the broadest possible coverage without giving up employment through spending down to get on Medicaid.

In terms of policy makers, it's an opportunity to get federal FFP for kids up to 300% of poverty. I should note, states do have the option within the law of going higher than that. But above 300% of poverty the state has to choose to pay. They may still choose to do that. It may be a worthwhile investment in the state's view, but the Feds won't provide FFP above that level. But it's an opportunity to expand the benefits of Medicaid to a broader group of kids. And particularly if states are in other ways already investing in payment for services for those kids, it may be a very clear saving to the state.

It also, I think, more subtly, maybe a saving in terms of things like school-based services investment in early intervention if that's not currently reimbursed by Medicaid in the state. So it's an opportunity to expand services to children and youth with special healthcare needs, bringing federal dollars into the state, providing better coverage to kids and, again, not creating this class of enforced poor families who have to spend down in order to get Medicaid when they need the expansive coverage for kids with special healthcare needs.

One other thing about FOA that is not true of the waivers is that it allows kids to buy into Medicaid as a wrap-around. So that states can sort of modulate the extent of coverage that they're providing to different families, using a sliding fee scale based on income to sort of make up the difference. So there's a lot of flexibility again in how states can use it to fill gaps in coverage for kids with special healthcare needs.

The focus why a law that focuses on this small group of kids, 12% of kids nationally, less than that since it's it requires you to be at SSI level, this is a group of kids whose family experience unique hardship financially related to raising kids. And are extremely vulnerable to the work consequences of having kids with special healthcare needs.

So it's a way of averting the impoverishment of a specific group of families in a state and attempting to begin to level the playing field for them.

Obviously, there are other ways to expand coverage. Right now there's of course a battle going on about the boundaries of SCHIP, but expanding SCHIP is another option. Katie Beckett or TEFRA waivers are still another option you can also create a Medicaid buy in program that's based in your state that's through a waiver rather than through FOA. So there are other ways to go about this. But FOA is an opportunity at sort of a national level that states can take advantage of.

I did want to note that there are three states that before the law was in effect had embarked on Medicaid buy-in programs. And one of the things that the Catalyst Center is hoping to do is to look at what the financial consequences has been in states that are planning a research project looking at the financial consequences in those states which are Vermont, Pennsylvania, Massachusetts. A number of other states have buy in for adults. These are the three states that have them for children that are open for children with special healthcare needs and what are the financial consequences for families in these three states of having these programs. So in essence what is the cost benefit ratio

been of programs in states where it's existed? We think that will be helpful to people who are thinking about programs in their own states.

The current status of Family Opportunity Act legislation, Donene is going to talk about our poster child of North Dakota, one of the states where the legislation has been passed. And there's interest and activity going on in a number of other states. This is based on a completely nonscientific approach of who has called the Catalyst Center or who do we know that is interested. You may be from another state that's not listed here and we'd be interested in hearing about it.

Our role in this, what we have attempted to do the Catalyst Center is to come up with a formula that states can use. A couple of your handouts actually deal with this one very specifically. The one on methodology, that talks about how we can go about helping you develop an estimate of what the take-up rate will be in your state of kids who are offered this option and therefore what the cost to the state will be.

That first round estimate of cost in your state is based on national data, not tailored to individual states where circumstances may differ in terms of things like the income distribution in your state, the take-up of SCHIP by kids at different levels. So what we

would like to do, if you are looking at this as a possibility for your state, is give you the first round very crude estimate. Then if you want to go further help you develop the more precise state level estimate.

And what we have found is that making this information available kind of lowers our name is the Catalyst Center and the idea of a catalyst is you lower the amount of energy required to make a change. And that's really what we are attempting to do in relation to states here is to sort of lower the threshold for pursuing the FOA opportunity.

And I want to say, in talking about that national strategy, that that's been very much a partnership with Family Voices in many cases it's the family leaders in states. And in a few cases it's been Medicaid or Title V that's contacted us. But often because this is an advocacy initiative, it's really the family leaders that have been able to be most up front about this.

It's been a wonderful partnership with Family Voices. I'm not going to go into the methodology in detail. I certainly will answer questions about it. I think it's more useful to think that through on a state-by-state level. But the basic message is that this is -- this should only be seen as one part of sort of armamentarian, an armory for addressing the

financial needs of families raising children with special healthcare needs. But clearly coverage is the starting place and comprehensive coverage is critical. Medicaid is our best route to it; and making Medicaid available to more families is just a wonderful opportunity. So now Donene can talk about how it actually happens.

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