

## **AMCHP 2007 ANNUAL CONFERENCE**

### **HEALTHY COMMUNITIES**

March 3rd to 7th, 2007

#### **HARDSHIPS AMONG FAMILIES OF CYSHCN**

CAROL TOBIAS: Before I start talking about another solution, or partial solution, anyway, to the issue of family financial hardship, I just wanted to mention that, Ralph said that the fund in New Jersey was copied by Massachusetts. I'm from Massachusetts. It's absolutely true. We copied it lock, stock, and barrel. The only thing is that we haven't raised the age yet. It was at 18, and it needs to go to 21, so we have our work cut out for us.

But there are a few other funds that are not quite as similar to New Jersey, but funds that operate like this around the country. The state of Michigan has a children's trust fund that's funded by a private bequeath of stock. I think it's been around since 1944. But it pays for the same kinds of things. And then Colorado and Georgia both operate trust funds for adults and children with brain injuries and spinal cord injuries. They're funneled through fines for people who are found driving under the influence. So, that's a much narrower scope of program, but other ideas like this that are funded through fines or private funds, or the employer contribution, I think they're a great idea.

So, with that, I want to turn to another potential solution to this problem, which is Medicaid buy-in programs, and the Family Opportunity Act. So, what is a buy-in program? It's a program that allows people who are over income from Medicaid to buy Medicaid coverage. And what makes it, what makes these programs special is that SCHIP, which often increases income eligibility for Medicaid, children, to be covered under SCHIP, have to be uninsured. If they have insurance, they don't qualify. But what if a family has insurance, it just doesn't cover what they need? They can buy into Medicaid under these programs for what we call wraparound services. Who is eligible? In the programs, there are about five or six Medicaid buy-in programs that I'm aware of around the country right now. Actually, there are many more than that because any state that has a program, ticket to work, work incentive program, has a Medicaid buy-in for adults, or maybe older teenagers, that if they go to work, people with disabilities who go to work can buy into the Medicaid program. But for children, the programs that exist now vary a great deal from, there's a program in Minnesota, which is called, the TEFRA Program. Basically a child has to be at an institutional level of care. In Massachusetts, the program, children has to just be eligible for SSI. And then there are a couple of states, I think New Jersey is one of them, but I know for sure Vermont is another, where any child, there's no critical eligibility whatsoever. Any child whose family is over income from Medicaid, up to 300% of the federal poverty level, can buy into Medicaid for wraparound coverage.

So, the programs, the Family Opportunity Act, which was passed as part of the Deficit Reduction Act, which people are really struggling with, in terms of some of the other provisions of the act, also includes provision for Medicaid buy-in. And under that program, the eligibility will be broader than that for TEFRA, or Katie Beckett or Home and Community Based Services. The children don't have to meet in an institutional level of care. It's for people who are going to, over income from Medicaid, and the Family Opportunity Act says you can actually, you don't need to have an income level, but the federal government's only going to reimburse you up to 300%. So a state could go higher at complete state expense. And it's also for families whose children have other insurance. Both uninsured and partially insured by other programs.

Let me talk a little bit about the state examples of the programs that exist now. And I'm going to start with Massachusetts because, Ralph, you said your Catastrophic Relief Fund was started in '88?

RALPH CONDO: Yes.

CAROL TOBIAS: That was a very good year. That's when the Massachusetts Common Health Program began. It's also when the Pennsylvania Program began. So, that's nearly 20 years ago. And I have to say, I worked in the Massachusetts Medicaid Program when this was implemented and actually ran it for a year. And it's hard to believe that it was that long ago. But, it was a buy-in

program for adults and children with disabilities. And the adult portion, the adults had to be working, going to work. So it's very much like a forerunner of the Ticket to Work and Work Incentive program.

And the children's portion, there was no work requirement, obviously. The Massachusetts program has no income limit, and has never had an income limit. It does have a premium schedule. And the premiums are on a sliding fee scale, based on family size and income. The program has evolved a lot over the years, but today, it covers over 3100 children. The services that are most commonly used by families in this program include transportation, dental care, some mental health services, and therapies. And the enrollment in the program has been very much affected by the premium, how they've set the premiums. So in the early days, the premiums were quite minimal, and there was a lot of enrollment. As they changed the premium schedules, I think a lot of families began to weigh off, do you want to pay a premium that high? Is it going to save you, are you going to save enough money, or are you just better off paying out of pocket what you don't, what your insurance company doesn't cover? Let me skip down to Pennsylvania. Because Pennsylvania has, actually, they don't have a buy-in program. It's free. At least last I checked, last summer.

UNKNOWN SPEAKER: Yeah, now, now (inaudible).

CAROL TOBIAS: It's still free? Okay. So, all right, Massachusetts, now Massachusetts is a smaller state than Pennsylvania. We've got 3300 kids. Pennsylvania has 32,000 children. The eligibility criteria are the child have to qualify clinically for SSI. There is no income limit. And there's no premiums. So basically, any child who qualifies for SSI can get Medicaid in Pennsylvania. They are talking about implementing a premium schedule. I imagine. But--

UNKNOWN SPEAKER: They are.

CAROL TOBIAS: They are. But I guess that hasn't happened yet. So that's the Pennsylvania example. Minnesota, as I mentioned earlier, it's really for their TEFRA Program, their Katie Beckett Program, and it's a buy-in, again, there's no upper income, it's, there's no income limit for families. And it's not, they don't really consider it a buy-in program. They ask for a family contribution once a year. So there's a family contribution.

And then finally, Vermont and New Jersey. And I want to just spend a minute on Vermont and New Jersey. Vermont is a tiny state. Really tiny state. Their Medicaid buy-in program is for children whose families are 225 to 300% of the federal poverty level. So it's a pretty small income range. And their SCHIP Program goes up to 300% of the federal poverty level. So, uninsured children get SCHIP. This is just for children who are under-insured. And the families can buy in. They have 1600 children on this program. Sixteen hundred. Like, half as many

as the Massachusetts program. There is no SSI eligibility criteria. It's any child. There is an income limits. It's 300% of the federal poverty level. And the set fee— actually they did this in part to help prevent families from dropping their insurance because SCHIP was a better deal. So SCHIP costs twice as much as this program. So if you have private insurance, and it's not enough for your child, you pay half as much as you would if you dropped it and went into SCHIP. It's about \$40 per family per month. And in talking with them, actually, we were on the phone with them again yesterday. They said actually, yes. Most of the children who have enrolled in this program are children with special healthcare needs. Cause that's who needs these extra services. If you have private insurance and your child doesn't have special needs, you know, your expenses are not that great. Why would you pay \$40 a month to join this? Mostly, but, it could be, as Ralph said, you know, the kid with the broken arm. I mean, there are children who have acute problems that might benefit from the Vermont/New Jersey example.

So, in Massachusetts, okay, so these are some of the most frequently used services in these programs. In Massachusetts, it's prescription drugs, therapies, and mental health, actually, are the three biggest things they spend money on. In Pennsylvania, same three things plus dental care. And in Vermont, it's dental care, prescription drugs, and personal care, actually, are the biggest things. For a lot of families, one of my colleagues at the Catalyst Center, May Komo, some of you may know her. She is the director of the Catalyst Center. Back in the day

when I was working for the Medicaid program and running the Common Health Program, she was one of the first family members who signed up for it. And a huge part of what she signed up for was for co-pays and deductibles, and transportation. You know, she had very, very good private insurance that covered, you know, unlimited physical therapy visits. But everyone had a \$15 co-pay. So that adds up pretty quickly. And, she joined the Common Health Program for that.

So just to go back to the Family Opportunity Act, again, it's part of the Deficit Reduction Act. It covers families up to 300% of the Federal Poverty Level with a federal match. And again, you can go higher without a federal match, uses the SSI Functional Criteria for children. It does include an option to charge premiums, and I imagine most states probably would. And it also has a premium assistance option. In other words, states can also help families purchase private insurance premiums. And Massachusetts and Vermont both have premium assistance programs built into their current existing Medicaid buy-in programs.

So, I just kind of want to summarize this session before we throw it open to questions and answers. You know, families of Children with Special Healthcare Needs face a lot of strains, as Amanda so eloquently put it. You know, strains related to complex decision-making, choices about where to live, when to work, are you doing enough for your child, not enough for your child, are you, what about the other kids in the family? Which doctor to go to, do you need a second

opinion, are you getting the right advice? It creates a lot of strain on individual parents, marriages, and siblings. We may not be able to solve all of those problems. But, we can do something. We don't have to let people go into poverty over this. There are some financial solutions that we can implement. This is a solvable problem. It's not that many children around the country. It's a huge expense for the individual families involved. But the reality is, it's not such a big cost, on a state-by-state basis for the government. Children with special healthcare needs are just a tiny fraction of the population. But lack of adequate financing creates a really large burden for individual families, and it just doesn't need to be that way.

And before I close, I just want to make sure everybody leaves with a copy of this book, if there's still some left on the back table. It's the Catalyst Center State-at-a-Glance chart book. It has information for, there is a sort of basic data for every state on National, from national sources that sort of give you a picture of the environment, the healthcare financing environment for children in the state. And then there's a section called innovations. And this, we did surveys of all the Title V Program directors, Medicaid programs, and family leaders in just about every state. And to identify, what are they doing to finance care for children with special healthcare needs that might just be a little bit outside the mainstream. And so, it's written up in here. And Ralph's program is one example. The Medicaid buy-in programs are another example. But there are probably 34 or 40 other examples

of ways to at least incrementally, you know, touch on this issue. So I hope everybody will take a copy on your way out.