

## **AMCHP 2007 ANNUAL CONFERENCE**

### **HEALTHY COMMUNITIES**

March 3rd to 7th, 2007

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

CAROL TOBIAS: Thank you and good morning everybody. I'm actually standing in today for Debbie Allen. How many of you here know Debbie Allen? Just about everybody, I guess. Anyway, Debbie put together this workshop, and then ended up having surgery, so she wasn't able to travel. But she's doing well. And I know that she wishes she could be here. And, so I'll do my best to take over her part of this workshop. What I wanted to start with today really isn't probably news to any of you. How many of you work in the field of Maternal and Child Health? Then I really probably don't need to tell you very much about family financial hardship. You probably know a lot about it. But, we've found that when we go out and talk to people about expanding care and coverage for children with special healthcare needs, the information that you sort of know intuitively from your experiences and your work with families is not necessarily common knowledge. A lot of policymakers will say to us, "But there's Medicaid. But there's SCHIP. But there's SSI. There's early intervention. There are developmental services. Why should we be worrying about expanding coverage for children with special healthcare needs?"

So what I want to start today with, I don't want to bore you. But I think it's really important to be able to make a case. We've done a little bit of research, and I'm

going to make the case, kind of from the data side of things and Amanda's going to make the case by providing a few examples. So what do we know about family financial hardship? From the National Survey of Children with Special Healthcare Needs, which I think many of you may know about. Sometimes it's called Slate's Data. They have a whole website, state-by-state information as well as national information. We know that 11% of families of children with special healthcare needs spent over \$1,000 a year out of pocket. So that's over a million families. And, a little over one and a half percent of them spent over \$5,000 out of pocket, and if you sort of do the arithmetic, at a most conservative estimate, if these families all spent \$1,001 each, you would get over \$1.6 billion, nationally. That's a lot of money for families to be spending.

From the same survey, we found that 20% of families of children with special healthcare needs reported that they experienced financial problems paying for the care of their children. So that's even, that's a lot more than the 11% that spent over \$1,000. You have to figure the extra, you know, families in this case, are families for whom spending 5, 6, \$700 per year creates a financial hardship for them. And there are many. The reporting of financial hardship occurs across all income levels. It's not just low-income families that experience hardship. But it's greater for low-income families. And you can see from the chart that families between zero and 199% of the federal poverty level, almost 30% of them said that they experienced financial hardship caring for their child with special

healthcare needs. And it drops down at higher income levels, but it's still a lot of people.

One thing that often gets lost in the discussions, and I think it's important, you know, stressing this when you're talking with policy makers about this issue, is that most of the care of children and youths with special healthcare needs is provided by the families themselves. And that, this has a major impact on employment for income. And from the same national survey, a third of all families of children with special healthcare needs reported that this affected their family employment. And that could mean everything from stopping, you know, from leaving the workforce in order to stay home and take care of a child, to reducing work hours, to turning down promotions. Things that might require a parent to work more hours, or to, you know, have to travel, or other kinds of things. Or, promotions that might bring them over income for public benefits, that would provide healthcare for their children and youth with special healthcare needs.

And there is a second survey that we've looked at, which is the National Longitudinal Survey of Youth. And this tracks youth into adulthood. And so in looking at this survey, we looked at youth who became mothers, who had children with special healthcare needs or disabilities. And we found that these, the mothers of these children are less than other mothers, and that the families of children with disabilities earn less and have a lower net worth than other families, which doesn't come as any surprise. But this is from national data sources. And I

think it's important when you're talking with folks, to stress these points. It has a big impact on family income.

So who is affected? Which families are affected? Actually, financial hardship is common across all families of children and youth with special healthcare needs, including families whose child, you know, is not in a wheelchair or not on a ventilator, but has a behavioral or cognitive condition. But there is a particular impact on single-parent families. Families of uninsured children, lower income families, and families whose child has a severe disability. So, it's common across all families. But these groups in particular face the financial hardships more.

A little bit about the impact of financial hardship, and then I want to hand it over to Amanda, who will talk not numbers, facts and figures, but real examples. One impact is medical debt. In a study of bankruptcies that was done recently, 50% of all bankruptcies in this country, personal bankruptcies, were caused by health, medical conditions. And this is for adults and children. And 13% of these medical bankruptcies are related to the care of a child. So that's pretty powerful impact.

Another impact is simply the child goes without the services that they need, because the family can't afford it. Other family members may be affected. There is less funds for food, clothing, housing, or education. And it can cause as many of you know, you know, marital and family stress.

So what are some of the pathways to hardship? How does this happen? Some of them include uncovered medical expenses. Things that aren't covered by insurance. Higher expenses, for everything that a family spends money on. So for example, every family spends money on utilities and housing. But if you're the parents of a child with special healthcare needs, you might have much higher electric bills. You may need to live in a particular neighborhood near family and friends, which you really can afford, but you need that support, or in a particular kind of housing that is more accessible. You know, everybody spends money on diapers for their children, but if the child continues to need them, you know, at older ages, then this family is spending a lot more on things that everybody spends money on. And finally the loss of employment income. So now I want to turn it over to Amanda to give a few examples from her own experiences as both a parent and an advocate about the impact of financial hardship on families.