

AMCHP 2007 ANNUAL CONFERENCE

HEALTHY COMMUNITIES

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HARDSHIPS AMONG FAMILIES OF CYSHCN

AMANDA HARNESS: First of all, I just want to say, this is a little bit of a daunting task for me to get up here and try to remotely represent the experiences of people in all different levels of income and throughout the entire country with many different needs. So, excuse me while I try to do this justice here. I do want to point out that in my particular circumstance, I'm going to get personal and just tell you a little bit about my life here. I had been working for the federal government for almost 10 years by the time my daughter was born. We had a little juggling system in my home where one of us worked days and one of us worked nights. I was the night provider. And when my daughter was born, unexpectedly, due to oxygen deprivation with cerebral palsy, there was, by the time we got into the first step system, which is the birth to three program in Missouri, before we even had our official diagnosis, we were, you know, suddenly in the lovely situation of having therapy five, six days a week, you know, throughout the day, doctors appointments, and I had a very difficult child to take care of on top of that, and I had to go from, you know, we went from a two-income household to a one-income household. Well, problem with that is that we had a two-income household debt. We had, you know, the House and the credit cards, which unfortunately everyone tends to get into, and it was devastating to

us financially. Both parents, we both had to declare bankruptcy and are trying to work our way out of that. So, I just want to point out that even though I am in a lower income bracket, I would definitely be considered below the poverty line at this point, and in the state of Missouri, that's probably much lower than it is in some of your states. I see parents everyday that are still managing with the two incomes and they're still losing their homes and losing their vehicles and having to declare bankruptcy. And it's almost like they're in a worse situation by continuing to try to be a two-income family. So I just kind of want to point out, sometimes the more you make, the harder it is.

Medical debt, which is what this is titled because when we were kind of working on the early stages of this, we were like, what do we call this? Well, medical debt is the easiest way to phrase it. But it really, this encompasses so much more than insurance costs, co-pays, although those can be a problem obviously. What it is is it's loss of income. It's one parent having to stay home, or it's one parent having to take a lesser paying job because it has more flexibility for appointments and sick days and whatnot. It's one parent, you know, going to part time position. There's also the loss of income from absences from work. And, you know, let me tell you. I mean, employers need you there. When you work a position, they expect you to be there. And FMLA is a wonderful kind of safeguard. But I will tell you that it doesn't keep you from losing income. And it unfortunately does not always keep you from losing your position, because while they may not say that is the reason why they get rid of you, when it comes time to downsize if your

company is having problems, you will be the first to go, unfortunately. I mean, I've heard it way too many times. Don't want to say that we don't want FMLA to be there, but it's not a foolproof. Then there are the expenses of daily life. When you take away the reduced income, there is also, you have to pay more. Some examples of that are needing larger vehicles or adapted vehicles. And, again, you know, when you don't have the income and you've got that increased expense, it's really difficult to get a car loan when you've declared bankruptcy, let me tell you. Then there are the expenses of having to purchase lifts or tie-downs for the vehicle. It would be a lot easier for me to tote my daughter's wheelchair around if I didn't have to lift it by hand to get it into the back of our vehicle that was purchased by family members and we're working on slowly doing what we can to pay them back. Eighty pounds several times a day is very difficult on you, physically. Let me tell you. It makes us not do as many things. Let's put it that way. Home modifications, such as ramps, which we still don't have on the front of hours, but I live in a ranch and I can handle the couple of stairs. Bathroom modifications. We were lucky enough, so to speak, to have our bathroom modified, thankfully, because my daughter is getting bigger and it's very difficult for me to carry her into the bathroom, but my doorway wasn't light enough. There wasn't enough room between the toilet and the tub. My father passed away and left me a little bit of money, and that was my bathroom modification. Five thousand dollars is not easy to come up with, for us. And there have been sporadic—I hear of—funding sources in this state, occasionally. And every time I

hear about them, they're gone by the time I can get my application in, and let me tell you, I'm on it when I hear about it. It's just so sporadic and so not consistent.

Then there are things like, you know, there is the equipment that insurance companies and Medicaid even won't pay for. My daughter needed a \$900 bath seat in order for me to bathe her safely. Now, I'm lucky in Missouri, Medicaid covered that. Some friends over in Kansas, they were on Medicaid, and they weren't covered. And trying to find them through the equipment recycle programs and whatnot is very difficult. Just as an example. And it's mesh and metal.

(laugh) Let me tell you. It's \$900. It's amazing. Childcare. So you do try to continue to work. Say you want to go to school, like I'm in nursing school now. The only reason I was able to do nursing school is because we happen to be in a big city. I live just outside of Kansas City, and there was an evening/weekend program. I'm trying to better myself. Had I not had the option of evening and weekends, I will never make enough money to, you know. Childcare is so difficult to find, and I live in Independence, Missouri. I live just outside of Kansas City, a large metropolitan area. I can list about three that handle young children like mine. And the waiting list can be very long. And it's more costly. And there's extra travel involved and whatnot. Gas and mileage for doctors visits, hospital visits, therapy visits, not to mention the wear on your vehicle. My daughter has been attending two hours of therapy five days a week right now. Downtown Kansas City, again, I live in the city, and I'm still driving 150 miles round-trip every week. There are people who live in rural areas who are having to drive an hour and a

half one way, you know, four or five days a week, due to catastrophic illnesses that their children have had.

Then there's increased utility expenses. You've got your people who need electronic medical equipment, such as ventilators. They have to buy things like generators because when the power goes out, their child still needs to breathe. They're very costly. Food expenses. For dietary reasons. Dietary supplements, things like Pediasure and Kindercal, we were lucky enough to have covered through WIC, until my daughter turned five in January. And, because she does not have a feeding tube, at least, in Missouri, Medicaid will not pay for her Pediasure. That's \$250 a month. That's my entire food budget. So, we are, thankfully, I have been connected with Children with Special Healthcare Needs, and they are a secondary payer and we're working on that one.

I know children with special healthcare needs exist. I can't tell you how many parents don't. Then there are newer treatments that you want to try for your child. You want to do what you can to help improve their health, their way of living. There are treatments like hyperbaric oxygen therapy that are not covered. And, people with greater incomes, I've seen actually try it. They use their savings. Some find it to be very beneficial. I can't do that for my child. Nutritional supports. I know a lot of parents have children with autism, which is just increasing in numbers. They find great benefit from doing special diets, such as gluten-free,

casein-free, and some different nutritional supports. It's very costly. They swear by it. They will give up their food budget in order to do that for their children.

Then we have smaller things that are still just as important. Things like special eating utensils that, you know, you have to pay for out of pocket. And let me tell you, if you haven't looked at a special-needs catalog, they get about 10 times as much for a spoon as we would have to pay, you know, at Wal-Mart. Door alarms to make sure that your kids are not leaving your home in the middle of the night when you don't want them to. Assistive communication devices and computer adaptations. My daughter can't speak. That's how she gets her, who she is across. That's how she gets her wants and needs across. And I qualify income-wise for what's called the TAP Program in Missouri. However, the income level on that, last I knew, was \$65,000. If you're talking a two-income family, that makes you out of that price range. These are all essential to if not life, to quality of life. And, if you're a parent, and you can't afford it, it's still something you want to do for, and you have to do it. There's the emotional cost of things like having to declare bankruptcy, losing your home. Relationship stress. Money is the biggest stressor of a marriage. Well, let me tell you, it gets harder (laugh) when you have a kid. I mean, besides the fact that you have a child who is usually needing more care, that's a stressful enough. Not being able to figure out how you're going to pay your house payment that month is more so.

Then there's the lack of funds for respite care. Two and a half years, it's been since my partner and I went to dinner. Literally. There is no money for it. And our family members are not physically able to carry, you know, Grandma's back's having problems and the other one's having some vision and she just can't, you know, where do you go? How do you keep a relationship alive when you can't go to dinner, go to a movie? How do you, it's very emotionally draining. Let's put it that way.

Not to mention the financial hardships if there is a divorce. Then you're splitting the two households and splitting that income. That's even more so. Then there's the fact that the long terms. The no retirement. No savings. If I had it, I could put \$999.99 into savings right now before losing Medicaid for my children. I have nothing to leave behind for my daughter, who is going to need a, she needs complete care right now, will probably always need it. What does that feel like as a parent to know that, you know, you're not leaving your child with anything, and how am I going to live when I do hit retirement age? There are just huge ramifications in the future to parents of these children also. You have to think about, you know, I'm behind when I do get my degree and finally get in the workforce and start saving. I'm about 15 years behind the average Joe. There are parents who don't seek medical care for themselves, and sometimes for their other children. Co-pays are way too much money. And medication is too expensive. So you prioritize your child's medical appointments over your own. You sometimes prioritize your child with special healthcare appointments. You

sometimes, you know, cut back on the preventive care. You postpone the eye doctor appointment. You postpone the well-child visit because you've already been to the specialist and you've already paid for their medicine co-pays and you're already looking at \$50 for the month and you just don't have anymore.

Support problems. So much is state-by-state, county by county. It's very difficult for a parent to know what programs there are out there. I have been actively involved in advocacy and learning since my daughter was about six months old. I've gone through Partners in Policy Making in Missouri just this last year, which I know is not in every state, but it's in several. It's an advocacy program for parents and adults, self advocates. It's a pretty good crash course. I'm still learning. I can tell you that the resources are not easily found. I know you guys are out there, but it's very difficult, unless you happen to meet the right person. Meet the, usually it's another parent. That is the best resource for the rest of us, is to learn, is through other parents. I know you guys do the best you can, and I appreciate what you guys are doing, even just by coming and listing and knowing that it's out there. I would propose that there be a more universal system, that it would be more easy to access, easy to find. Have consistent funding and be, you know, more visible.

And basically, you know, your entire life changes. And without these supports, you really feel like you're drowning. It's insurmountable. And the programs need to be available nationwide consistently and adequately funded. And I really

appreciate you guys listening to my layman's speech here today. But, I hope I've done it justice and I hope that you will at least try to seek ways around this problem. So thank you.