

Healthcare Costs for the Insured with Significant Health Problems

I'm here to talk to you today because I would like you to understand my family's health care needs as you make decisions on healthcare legislation. Our story is not short and simple, but neither is the healthcare system. I know that you make policy based on an entire system with many conflicting needs and priorities, and that is necessary, but I think that our situation illustrates key problems with the health care costs in our country.

I didn't fully understand the costs of healthcare until I had a daughter with a few rare, complex and dangerous chronic medical conditions. Not that it's relevant to my message but to provide some background my daughter has dysautonomia, gastroparesis, postural orthostatic tachycardia syndrome (POTS) and complex regional pain syndrome (CRPS). Her medical team also thinks it's likely that she has a form of mitochondrial disease although in a milder form than many who are afflicted with those diseases. Also, the early childhood trauma from her illnesses and surgeries has left her with PTSD. Based on these conditions, Meg is seeing or has seen specialists in four states and had surgery in three. She currently sees two specialists at the Cleveland Clinic, two in Rochester and one at University Hospitals Cleveland. At times she has needed VPAP treatment, alarming overnight oxygen monitoring, and a wheelchair. She needs many medications and at times extensive occupational and physical therapy. To say that her care has been expensive is an almost ludicrous understatement.

To say that I am only worried about insurance for pre-existing conditions would also be ridiculous. The costs of care for someone with a chronic condition are unmanageable even for someone with insurance. Let me illustrate the problem by using my family as an example.

First, you should know that we have the best plan that my husband's job offers, it's highly subsidized by his employer and is a high deductible plan. After a significant employer subsidy, the plan costs our family \$5400 annually. We reach our full family deductible or come very close every year, so our covered medical expenses are \$6000 per year or the amount of the deductible on the plan.

There are also uncovered medical expenses. My daughter takes something known as the "mito cocktail" which is a regimen of high doses of a variety of supplements every month costing about \$660 per year. None of that is covered. We also need to travel to the Cleveland Clinic or the Pittsburgh Children's Hospital, typically spending the night because of the time it takes to see multiple specialists and get the required labs completed. At two trips per year on average the cost comes to about \$400 per year.

So even with the best medical insurance that we have access to our family medical expenses are \$12,460 per year or \$1038 per month. If we had to pay the full cost of health insurance, those numbers would be \$23,460 per year or \$1955 per month. Please let those numbers sink in. Think about what those numbers mean to families. According to the Census Bureau, the median income for 2018 was \$63,179. That means that the cost of health insurance would be over 20% of their income with the employer subsidy and almost 37% without the help of an employer subsidy. How is this OK?

My family is lucky. So far we've been able to afford this. It's a big hit, but at least we do not have to choose to pay the rent or buy our child's medicine. For most parents though that amount of money is totally unsustainable. Their children would go without much-needed

medication. They wouldn't get to see the specialists we've seen around the country that got my daughter out of her wheelchair. Their life expectancy would be dramatically shorter. Is this the best our country can do?

The plans that are currently being suggested nationally won't begin to solve my problems. We have a Health Savings Account, and we put the maximum allowed by law into it every year. We aren't getting ahead or saving for a rainy day with that, because we spend it all every year. It was a tough hurdle to reach because the first year we had to pay for the expenses and put into the account for future years, so it cost us double that year. Again, this is not even remotely reasonable for most families.

Current plans on the table suggest that competition will make the insurance industry more competitive but does anyone really believe it will drop the numbers enough to make it reasonably affordable for a family that has someone in the household with a significant chronic illness? These families can't buy cheaper plans with higher deductibles because they are going to have high healthcare costs, day after day, year after year. Even if competition dropped the cost of needed insurance by 20%, it's still totally out of reach. And, does anyone think it would actually drop that much?

Health savings accounts are also impractical for most families dealing with chronic illness. They can't build up a reserve in an HSA because they'll spend it every year and they're unlikely to be able to save anything anyway given the burden they're already bearing.

The Affordable Care Act at least provided insurance at a reasonable rate and got more people covered. I'm a big fan, but it's not enough. As you can see by my calculations even good insurance doesn't cut it for the majority of families dealing with chronic illness.

My daughter is 18 and doing pretty well these days. She's out of her wheelchair and going to school. She will never be as healthy as the average kid, but she's "optimized" for her condition. All our children deserve that opportunity. Right now they don't have it. The Affordable Care Act didn't go far enough. The currently proposed adjustments are quite frankly laughable and out of touch.

Of course, the problem isn't only with children, my mother died last year from cancer at 77-years of age. Her treatments were very expensive and not fully covered by Medicare, so despite her age and illness, she had to keep her job to have supplemental insurance that allowed her to afford her medication. So, instead of spending her last few months with her family she worked to keep herself alive a little longer. This is a tragedy that should not be taking place in a civilized society.

Here's my plea. Fix it. If the country as a whole can't do it, make New York state a shining example of how to do right by its citizens. We are better than this.

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