Health care in America: For one family, a $300,000 debt nightmare

January 29 2020

The Maccoux family receive visitors to their beautiful home in a Minneapolis suburb with an infectious warmth that belies the fact their youngest daughter Olivia has had more than 140 brain surgeries, all by the age of 24.

Mom Cathy smiles tenderly as she scrolls through photos of Olivia on hospital beds at various ages, from a baby to toddler to a teen.

"That's just a hole in her skull from one of the shunts, isn't that crazy?" she says.

And dad, Dan, is close to laughing as he reads from bills sprawled out on a table cataloguing medical costs going back to 1996—including parking tickets and hospital meals.

"Very surprisingly, very few people have a love of records," says the 57-year-old independent consultant in the semiconductor industry.

The family's case is a telling illustration of the flaws of the US health care system, which Democratic candidates for the White House have promised to overhaul or scrap ahead of their first primary contests in February.

Despite spending the most on health care in the world, 27.5 million Americans are without any health insurance.

And for the "lucky" insured, sky high costs can lead many to bankruptcy, or as in the case of the Maccoux, indebted for life.

Olivia was born three months early, which is at the root of her misfortunes.

She has a rare condition called hydrocephalus, meaning fluids build up in the cavities of her brain that require valves and catheters to drain down toward the abdomen.

But the devices have needed to be changed dozens of times—not to say anything of the epilepsy she experiences, among several other neurological conditions.

"I grew up with no hair," she says of her childhood.

But the Maccoux family are fortunate in one respect: Dan has a six figure income, and has always had health insurance.

When he worked for a company, his insurance coverage was "gold," he says.

The problem is that in the US, coverage rarely covers 100 percent of people's needs. The system is largely privatized, and reimbursements to patients depend on negotiations between a hospital or pharmacy and the insurer.

The level of reimbursement varies from case to case. There are different levels of "deductibles"—the amount paid by the patient before the insurance kicks in, as well as "copays," the fixed amount of out-of-pocket costs for doctor visits or drugs once the deductible has been met.

"It was the copays I think that killed us because we had so many appointments," said Cathy. "We were drowning for a while because it was just constant, constant."

Advised to divorce

Dan sat with an AFP team and added up the columns on spreadsheets he has used to calculate costs since 2005, the year he began documenting expenses in detail (before that, he has estimates).

Across a total of 15 years, it came to $100,000 for out-of-pocket costs, $22,000 for prescription co-pays, $15,000 for meals during hospitalization...with provider co-pays and parking thrown in, totaling $192,000.

From 1996 to 2004, he estimates the costs were around $130,000—with the two figures combining to around $322,000.

"Considering the catastrophe, we did relatively good," said Dan. "We probably had a couple dozen times where a provider turned it over to a debt collector and those situations were probably the hardest to deal with."

The house in which they live has served as a piggy bank for their debts: the family has borrowed money by remortgaging it, a permanent financial juggle.

In 2001, their woes multiplied when their second youngest, Traci was diagnosed at the age of 11 with complex regional pain syndrome, a rare affliction that started in her leg and spread to her arms (their eldest, Amanda, is fine).

The family has on occasion turned to GoFundMe to raise money for the two; the platform has become indispensable for Americans trapped in medical debt.

"We've had people tell us you should get a divorce," said Cathy, as a financial strategy. Under this plan, she would have taken custody of the children and, without being employed, would have benefited from public coverage.

The couple never considered it.

Obamacare, the insurance reforms enacted by former president Barack Obama in 2010, helped the family by removing lifetime caps previously imposed by insurance companies on their payouts.

It also prevented insurers from refusing patients coverage on the basis of having a pre-existing conditions—something that would have made the family pariahs when Dan left his company and went freelance.

In the last few years, things have improved markedly, said Dan. Olivia and Traci are still sick, but have successfully moved to state health insurance, a more comprehensive package that reduces the burden of out-of-pocket costs on the family.

Olivia finished college last year. "Neurologically I'm doing a lot better," she said.

But the system isn't finished yet with the parents. While Obamacare helped the family in some ways, it also sent their insurance premiums soaring. For this year, Dan and Cathy are paying $1,261 a month. Any reimbursements won't kick-in until they reach their annual deductible of $6,400 each.

"We all have to laugh," said Dan. While his friends are discussing their retirement plans, "I'm like, I'll never be able to retire!"