



Complex Child E-Magazine

www.ComplexChild.com

The Hidden Financial Costs of Having a Child with Special Needs

Part 1: The Problem

by Susan Agrawal

This is Part 1 of a two-part series. This month we take a look at the many hidden financial costs of having a child with special needs. Next month, we will discuss solutions to minimize these hidden costs and prepare for future costs.

We are fortunate to have good private insurance as well as a secondary Medicaid waiver for our daughter with special needs. Most people would think that having two insurances would mean that my daughter's medical needs would be met sufficiently. As those of us with children who are medically complex know very well, that is simply not the case.

There are many, many hidden financial costs of parenting a child with special needs, and most of these would not even cross the minds of the average person or politician. These include lost work hours, paying out-of-pocket for denied items and services, and needing expensive non-covered items, to name just a few.

In this article, I will outline some of these hidden financial costs. While this may seem like a depressing litany to some, I think it is very important for families to know what to expect from a financial point of view so they can manage their finances to the best of their abilities. I also think it is critical that those involved in making health policy decisions have a clear picture of all the indirect costs of having a child with special needs. This month we will take a look at the problems, and next month, in Part 2 of the article, we will evaluate some ideas for minimizing these hidden costs.

Lost Productivity

Before my daughter was born, I was a fellow and faculty member completing my PhD at a major research university. While the amount of money I made was not tremendous, it was a large portion of our income at the time, and my salary likely would have increased dramatically upon completion of my degree. After my daughter was born, I had to stop working, though I did eventually complete my degree. Her care was simply too time-consuming for me to be able to work at all.

In my state, it is very difficult to qualify for nursing services, and my daughter did not qualify until she was three and had her central line placed. Because we did not qualify

for nursing and my state has few medical day care programs, the only way I could continue working would be if I could find a caregiver willing to care for a child with a feeding tube who screamed 16 hours a day, vomited 20 or more times a day, and had daily seizures. Needless to say, it is virtually impossible to find a caregiver willing to work with a child like my daughter. Even if we had been able to find someone, the cost likely would have been very high.

Like many parents of children with complex medical needs, I left the workforce. Six and a half years later, I am still out of the workforce, though I am able to do some freelance work from home. We are fortunate that we can survive on just one income. Many families are not as fortunate, and are forced to make very difficult decisions because a parent simply must stay home to care for the child with special needs.

Even those parents who are able to work will suffer a loss in productivity. Many will need to miss days of work and pay when their child is sick, when the child's nurse does not show up, and when emergencies and hospital stays occur. Many parents will even end up losing their jobs due to frequently missed work.

Lost productivity is a lose-lose situation for everyone. Not only do we lose members of our workforce, but parents also lose their financial security by having to give up their jobs.

Hours of Uncompensated Time

Most parents of children with special needs know the drill. When it comes to insurance, doctors, and benefit programs, everything is a battle, and only the most persistent parent can win the battle. Like most parents in my shoes, I average at least an hour a day on the phone or writing letters to obtain basic medical and educational care for my daughter.

Much of my time is spent dealing with our private insurance company, whose policy is to deny, deny, deny. Almost every piece of equipment my daughter has ever needed, including her wheelchair, bed, and respiratory vest, has been denied two or more times. Each denial means I need to get her doctor to write a new letter, track down more medical records, and compose another letter myself.

Then there are those items that insurance refuses to cover that you know you could get them to cover if you are just willing to fight for it. For example, we had a prescription not covered for \$48. I knew I could fight to get it covered, but it would have taken at least five hours of my time, and I felt my time was not worth the \$48. Anything under \$50 I typically just let go.

I also spend a lot of time fighting for my daughter to get an appropriate education, filling out forms for medical visits, therapies, and benefit programs, and fighting it out with home health agencies who never seem to get orders right the first (or second) time. There

is also the time spent making appointments, applying for grants, and simply doing medical research to find better ways to treat my child.

If I were a professional paid to do this job, I would probably be earning at least \$500 a week in pay. Instead, all of my hours are completely uncompensated. We are required to do the work of a professional administrative assistant for no pay, or our children simply will not get the care they need.

Paying Out-of-Pocket

We have pretty good insurance, a PPO plan that is reasonably generous with a low deductible, though we do pay high premiums to keep this plan. In any case, there are still hundreds of items each year that I need to pay for out-of-pocket because insurance will not cover them.

Six boxes of Infant Ibuprofen (\$30 a week), microwaveable washcloths since my child cannot bathe daily with her central line, the compounding agent for her reflux medication (\$15 every six days), wipes, chux, tape, gauze, distilled water, and Betadine. Those are just a few of the items we have needed on a daily basis that were not covered by insurance. We are fortunate, because many families also need to pay for formula (as much as \$2000 a month) and other supplies that are not covered.

Other larger items are often deemed "items of convenience" and subsequently denied by insurance. Here are just a few we have purchased recently: a special needs car seat (\$500), a bath chair (\$500), a supportive swing and heavy-duty swing frame (\$300), a used special needs stroller (\$200), adapted switches (\$30-\$250 each), assistive technology items (\$50-\$300 each), and special switch computer software (\$100-\$200 each). Many families also have to purchase their own communicators (\$3000-\$10,000), gait trainers, standers, and other equipment. In many cases, families simply go without. My daughter really needs a soft adapted seating chair for home, but we cannot afford it, so she uses a regular recliner instead, which is definitely contributing to her worsening scoliosis.

There are also many cases in which home health agencies will only provide substandard equipment and supplies, and you end up having to purchase your own items to provide appropriate care for your child. For example, my daughter's respiratory company will only provide us with a \$36 nebulizer. It works pretty much like you would expect a \$36 nebulizer to work. It takes a good 45 minutes for each treatment and only works if the child is completely upright. Since having to get nebulizer treatments for as long as 90 minutes stresses my daughter out, we are buying our own nebulizer instead. Of course, now I also have to buy all the supplies for it as well. We have had similar experiences with other respiratory items, syringes, and gauze, to name just a few.

Everything—and I mean everything—associated with special needs and intensive medical needs is unbelievably expensive. On a day-to-day basis, the average family of a

child with special needs will be paying as much as two or three times as much per item for clothing, toys, and other specialty items. Take, for example, a simple cause and effect toy commercially available for \$10. The switch-adapted version for children with mobility impairments is \$50. Special adapted toys routinely run from \$50-\$200. Clothing like a wheelchair cape will cost \$75-\$100 or more. Cooling vests are as much as \$150 or more. The regular baby Bumbo chair is about \$40, while the special needs version runs \$200.

Other out-of-pocket expenses include prescription copayments, doctor copayments and coinsurance, and insurance deductibles. If your child takes 15 different prescriptions and each one requires a \$30 copay a month, that adds up to \$450 a month, just in prescriptions. Four trips to different specialists a month may be another \$150-\$200 in copays. Some plans have high deductibles, sometimes as high as \$5000 a year before anything is covered. The costs easily add up to thousands of dollars per year.

Add in other out-of-pocket expenses like gas for driving to and from appointments and travel for specialized medical care, and it quickly adds up to an average of \$10,000-\$20,000 a year. It is an unbelievable amount, and can easily push even a well-to-do family into financial ruin.

The High Costs of Good Doctors, Therapists, and Other Professionals

When your child has complex medical issues, oftentimes you need exceptionally specialized care. Sometimes there is only one doctor in your city—or the country—who can provide the expertise you need to treat your child. Similarly, your child may need specialized feeding therapy from an occupational therapist, or augmentative communication training from a speech therapist.

But much of the time, your insurance company restricts which doctors and therapists you are allowed to see. You are often only permitted to see “in-network” providers, and second opinions are not considered necessary. In addition, some of these doctors and specialized therapists do not even take insurance.

Like many families, we had to pay out-of-pocket for specialized training on my daughter’s communicator because her therapy center did not take insurance. At \$135 per weekly session, it quickly added up. Other families have had to pay for nontraditional therapies, including conductive education, intensive physical therapy, ABA programs, and similar other services out-of-pocket at a very high cost.

It is not uncommon for families to also require private educational assessments, a special education lawyer, or a special needs advocate when dealing with the school system. These, too, are exceptionally costly, but are often the only way to meet your child’s educational needs appropriately.

Many families end up paying thousands of dollars out-of-pocket for medical specialists, second opinions, specialized therapies, alternative treatments, and educational expenses. While sometimes insurance can be convinced to pay for some of this care, it is often up to the parent to shoulder much of the financial burden.

The Cost of an Accessible Lifestyle

Like many families, we had a lot of special considerations when we went to buy our first home. It needed to have a first floor bedroom and bathroom, an open floor plan, and a potential way to add a lift on to the back of the house. We found a home that met our needs, but we definitely paid a higher price than we would have if we could have chosen another style of home.

Every step of the way, housing and transportation for children with special needs is much more expensive. For example, we had to upgrade all of the electrical in my daughter's room to accommodate her medical equipment. Many families need to renovate a bedroom or bathroom—or both—to allow them to care for their children appropriately, often at a cost of \$10,000-\$20,000. While we have not done this yet, we did have to add a back deck with a lift to get my daughter in and out of the house. This \$13,000 project was mostly funded by a grant, fortunately, but many families need to shoulder the entire cost themselves.

We also needed a van that could accommodate a wheelchair and the rest of our family. This is a second car for our family, and a vehicle we probably would not have ever purchased otherwise. While we were extremely fortunate to get Medicaid funding to pay for a lift and tie-downs for the van, we still had to buy the van ourselves, as well as pay for insurance on it. And, not surprisingly, it gets terrible gas mileage, 12mpg, so we pay a ton for gas when we drive it.

These hidden costs are considered "normal" expenses of daily life, and typically are not reimbursed or even considered by most insurers.

Holding on to Benefits: A Microcosm of the Problem

My daughter currently is part of a secondary Medicaid waiver that has reduced our out-of-pocket expenses by about \$10,000 per year. But in order to keep her eligibility for this and other government benefit programs, she can never show any substantial income and assets. This is not a problem currently since she has neither, but if anyone leaves her an inheritance or we pass away and she receives life insurance funds, she will lose her Medicaid coverage and benefits.

There is a way to protect her money, through a special needs trust that allows the money to be held in a trust for her care. And—you guessed it—special needs trusts cost a fortune, usually between \$2000 and \$5000.

So, in order to make sure she is eligible for programs that will dramatically reduce her out-of-pocket expenses, we get to pay a small fortune.

It's just another example of how costly caring for a child with special needs really is. It's no wonder so many families go bankrupt trying to meet their children's needs. At tens of thousands of dollars per year, it is almost impossible for many families to survive.

But there definitely are ways you can improve your financial situation. Some of these strategies include maximizing your child's benefits, learning how to "work" the insurance system, knowing your rights as an employee, participating in equipment exchanges, and encouraging local and federal governments to make reforms that improve your situation. These strategies, as well as several others, will be discussed in Part 2 of this article next month.