



Complex Child E-Magazine

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The Hidden Financial Costs of Having a Child with Special Needs

Part 2: The Solutions

by Susan Agrawal

This is Part 2 of a two-part series. Last month we took a look at the many hidden financial costs of having a child with special needs. This month, we discuss solutions to minimize these hidden costs and prepare for future costs.

The average child costs around \$15,000 a year to raise in the United States.¹ You can expect to almost double this number if you have a child with complex medical needs and typical insurance coverage. How can families survive and prevent bankruptcy or foreclosure when dealing with such high costs?

While financial ruin due to your child's medical condition is not always preventable, it can be minimized with proper planning. This article will provide some general tips to decrease current expenses and prepare for future expenses.

Plan Ahead

The best strategy for preserving your financial security is to plan ahead. Planning ahead is probably the only thing that can save your family from ruin when an expensive medical crisis does occur. If you have the money, consider contacting a special needs financial planner who can help you develop a comprehensive plan for now and the future. If this is out of reach, as it is for most families, there are books available to help guide you through the process, such as *The Special Needs Planning Guide* by John W. Nadworny and Cynthia R. Haddad.

Every family should have a budget and each parent needs to be keenly aware of how much money is coming in and out at all times. For parents of children with special needs, it is often useful to “audit” your child's monthly expenses, looking at your child's costs for the previous few months to help you anticipate costs for the future. See the sample Medical-Financial Audit below, which allows you to calculate your child's expenses.

It is also important to always have a back-up fund available. Ideally, it should provide enough money for your family to survive for six to eight months, but anything is better

than nothing. Our family automatically transfers a few hundred dollars each month to college and emergency funds.

Medical-Financial Audit Checklist

	Monthly Cost
Insurance Premium	
Insurance Deductible	
Physician Copays	
Physician Coinsurance	
Prescription Copays	
Therapy Copays	
Home Health Coinsurance	
Other Medical Copays	
Medical Supplies	
Diapers/Personal Care	
Medical Food	
OTC Items	
Travel/Gas	
Childcare/Nursing/Respite	
Other:	
Other:	
Other:	
MONTHLY TOTAL	

When looking for work, it is extremely important to consider the benefits offered with each position, if any, to determine how they will affect your costs in both the short and long term. Obviously, in these economic times a job with poor benefits is better than no job, but if the option is there, choose wisely.

While the focus here is mostly focuses on day-to-day financial choices, thinking about the future is definitely important as well. You will need to plan for your child's care if you pass away, and you will need to create a will or trust to provide for your child. I also highly recommend setting up a special needs trust to protect your child's money or inheritance while still allowing eligibility for public benefits. These trusts are very expensive but also very necessary.

Most importantly, always expect the unexpected. Have contingency plans in place so you can survive if you lose your job, if you get sick or injured, if your child needs to be in the hospital long term, or if you lose your home.

Maximize Benefits

A recent article in *Pediatrics* evaluated the rates of underinsurance for children with special needs in each state of the United States.² Not surprisingly, 24 to 38 percent of children were considered underinsured, meaning their basic health care needs were not being met. Overall, nationally and in almost all states, children with private insurance had higher rates of underinsurance than those on Medicaid.

Underinsurance means that families are paying out-of-pocket for services that insurance should be covering in order to fully meet their health needs. In order to minimize these out-of-pocket expenses, it is important to maximize the benefits available to your child.

First of all, determine what public benefit programs are available in your area. All states have a variety of federally mandated programs available to serve children with special needs, and many of these programs will provide secondary Medicaid coverage. Programs include Medicaid waiver programs, SSI, Early Intervention, Title V programs, CHIP, and WIC. A previous article on this subject, “Federal and State Assistance Programs for Children with Special Needs,” [<http://articles.complexchild.com/May2009/00123.html>] discussed many of the programs available in detail.

It is important to apply for all programs even if you are not sure you qualify. A counselor may even tell you that you do not qualify. Apply anyway, because in some states counselors are encouraged to discourage families from applying.

It is also important to apply for programs even if you are not sure you need the full range of services offered through the program. Many have long waiting lists, and your child may very well need those services by the time he or she comes to the top of the waiting list. In addition, if you are denied for services, definitely appeal or re-apply, as many of these services, and especially SSI, deny the majority of all applicants the first time around.

It is also important to maximize your current insurance benefits. Do not let your insurer get away with denying items or services you feel should be covered. Many insurers use the “hassle-factor” approach to approving claims. They deny everything on the first pass in hopes that you will not go through the hassle of appealing. When you do appeal, more often than not you will win. See the previous article on writing insurance letters for some strategies on writing insurance appeal letters.
[<http://www.articles.complexchild.com/00012.html>]

Seek Out Free Assistance

Some of the higher cost services involved in caring for a child for special needs, such as legal or advocacy services, are not covered by insurance. This does not mean these services are unavailable to you. Each state is mandated to have a resource center for families dealing with disability. Many of these centers provide free, personalized

counseling, as well as training sessions, on topics including special education services and obtaining benefits. You can search for your family resource center by visiting the website for the Technical Assistance Alliance, at <http://www.taalliance.org/ptidirectory/pclist.asp>. I have discussed my daughter's education situation at length with a counselor at one of these centers and was very pleased with the resources I was provided.

A growing trend is free or inexpensive services from a Medical-Legal Partnership. These partnerships pair lawyers trained in subjects relating to medical care and disability with medical centers and families that need their assistance. The National Center for Medical-Legal Partnership at <http://www.medical-legalpartnership.org/mlp-network> lists the programs currently available throughout the United States. These lawyers are willing to help you obtain benefits when benefits are denied, ensure appropriate educational services are provided, challenge your insurance company, and even sue your state or local government to provide services or benefits.

Free legal clinics are available throughout the United States, often through the Legal Services Corporation [<http://www.lsc.gov/>] or local law schools. While these may not have experience with children with special needs, they may be able to help you with other legal issues, including housing and financial issues. Some law firms also take cases for free as part of their charity programs. It never hurts to ask.

Certain groups, such as Easter Seals, ARC, and UCP, provide free services to families. These vary by region, but may include counseling, assistive technology, medical day care, and other programs.

Shriners Hospitals, as well as other hospitals such as St. Jude, provide free medical care to children with certain conditions. We have had wonderful experiences with Shriners and would highly recommend them to other families. Services we have received include orthopedic care, braces and splints, equipment, surgery, and even a stay in the PICU.

Many cities and states provide free medical clinics. While some of these may not be prepared to meet the needs of a child who is medically complex, most can provide some general services, such as well-child care and vaccinations. Some, especially those in large cities, may provide a full range of specialty services.

Other free programs in your area may include food banks or clinics, donation programs for clothes and household goods, and financial assistance programs.

Local support groups and parent-to-parent groups can also be extremely helpful. These groups are filled with parents who have been in your situation before, and can often guide you to find local services that could benefit you.

Use Your Tax Benefits

The money you spend on medical equipment, supplies, copays, coinsurance, and other out-of-pocket expenses can be tax-free much of the time. If you work for a large employer, you may be able to have money deducted from your paycheck into a Flexible Spending Account for medical expenses. This money is tax-free and can be spent on any qualifying expense incurred within the calendar or plan year. Beginning at the end of this year, contributions will be limited to \$2500, and some companies may choose to lower this maximum even further.

Another possibility is a Health Savings Account, available only to individuals with a high deductible health plan. In this scenario, participating individuals may contribute money tax-free to a savings account to use to pay for medical expenses. Currently, families may contribute a maximum of about \$6000 per year to the account.

It is also standard to deduct the cost of your health insurance premiums from your paycheck before taxes, meaning that your premiums are tax-free.

If you spend more than 7.5% of your income on medical expenses, you can qualify for a medical expenses deduction on your taxes. You must itemize your taxes and enter your medical expenses with your other deductions. This allows you to subtract any money spent on medical expenses from your income, thus making it tax-free. In addition, you can deduct the cost of your insurance premiums as a medical expense if you paid for them and they were not taken out of your paycheck before taxes. Note that you typically cannot use both a Flexible Spending Account and deduct medical expenses unless you can achieve the 7.5% level even after subtracting out the money from your Flexible Spending Account.

Finally, don't neglect the Child Tax Credit and Earned Income Tax Credit. These credits apply to any child and may give you a credit or even a refund, even if you do not make enough money to pay taxes.

Recycle Your Equipment, Buy Used, and Shop Smart

As we all know, anything labeled "special needs" automatically means the cost is double or triple what it should be. Equipment and supplies are marked up dramatically, and home health agencies may inflate costs even more. Nonetheless, it is possible to minimize costs and still get your child all the supplies he or she needs.

First of all, consider lending or borrowing. Many items, such as standers and walkers, can be borrowed from hospitals, rehab facilities, or organizations like UCP, Easter Seals, or Shriners. This is particularly useful for more short-term or trial items. In addition, there are many toy lending libraries, such as Lekotek, that allow you to borrow adapted toys, software, and other items. See this previous article on toy lending programs:

<http://www.articles.complexchild.com/June2008/00044.html>. It may also be possible to borrow items from another family who is no longer using them.

Make a point to recycle your equipment and supplies, and donate or sell any items you do not need. Most states sponsor an equipment exchange, and there are several online groups dedicated to facilitating equipment exchange, as described in this earlier article, <http://www.articles.complexchild.com/00015.html>. Many families and organizations are willing to provide items just for the cost of shipping.

If you do need to purchase items yourself, make sure to shop smart. Many medical items are available used or new through medical discounters who sell on Ebay. We have purchased medical supplies from Ebay many times, often at half the cost. Also consider buying items out of pocket if your home health agency jacks up the price so high that the copay or coinsurance is greater than the cost of the item purchased out-of-pocket. And yes, this does actually happen!

Grant Programs and Charities

We live in a world filled with many kind people and lots of great charities that may assist with the purchase of medical supplies or paying medical bills. Here are just a few that are willing to help in this area:

- UnitedHealthCare Children's Foundation: <http://www.uhccf.org/>
- The Morgan Project: <http://www.themorganproject.org/>
- Building Blocks for Kids: <http://www.bb4k.org>
- Aubrey Rose Foundation: <http://www.aubreyrose.org>
- Variety Mobility Program:
http://www.varietychildrenscharity.org/variety_programs/mobility_program.php
- Challenged America: <http://www.challengedamerica.com/>
- Jessica's Hope Chest: <http://www.4jhc.org/>
- First Hand Foundation: <http://www.cerner.com/firsthand/>
- Modest Needs: <http://www.modestneeds.org/>

There are also many local or condition-specific charity programs available that may provide assistance.

Advocacy

Advocacy is a strategy that cannot be overlooked. Encouraging your state and federal government to shape and pass laws beneficial to children with special needs is one of the best ways to protect yourself financially. For example, the recently passed ObamaCare bill, while highly controversial, contains several provisions that will make a huge difference financially for children with special needs. These include eliminating pre-existing condition clauses in health insurance policies, extending benefits to children up

to age 26, eliminating lifetime maximums, limiting out-of-pocket expenses (copays and coinsurance) to \$10,000 per family, covering preventative services free of charge, and mandating insurance coverage for habilitative (non-rehab) therapy. While this legislation is not perfect, it does make several strides toward improving the situation for families with extraordinary medical expenses.

Other forms of advocacy may also lead to favorable reductions in expenses. For example, some countries and states pay a parent to stay home and take care of a child with a significant disability. Others have extensive Medicaid waivers that cover extraordinary expenses. Advocating for programs like these will ensure that your family, and other families in the future, will not go bankrupt trying to care for their children with special needs.

Take Stock

The time to get in control of your financial situation is now, especially in these difficult economic times. Make sure you plan ahead, minimize expenses, and maximize benefits. While even the best planning sometimes is not successful, more often than not you can preserve your family's financial stability with just a little forethought.

¹ <http://moneycentral.msn.com/content/collegeandfamily/raisekids/p37245.asp>

² Michael D. Kogan, *et al.* State Variation in Underinsurance Among Children With Special Health Care Needs in the United States. *Pediatrics* 2010;125(4):673-80.