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PATIENT MONEY

Dealing With the Financial Burden of Autism

By WALECIA KONRAD

WHEN Jeff Sell's twin sons were found to have autism 13 years ago, he, like so many other parents in the same situation, found himself with a million questions: Will my children be able to function? What are the best treatments and where do I find them? How will this affect the rest of my family?

And besides those monumental worries, Mr. Sell kept asking himself another fundamental question as he began the long string of doctor and therapist visits with his sons: "How in the world am I going to pay for all this?"

Autism trends, treatments and therapies routinely make headlines. Often overlooked, though, is the financial burden for many families with autistic children.

Treatment is extremely expensive. Direct medical and nonmedical costs can add up to as much as \$72,000 a year for someone with an extreme case of the disorder, and even \$67,000 a year for those on the lower end of the spectrum, according to a study from the Harvard School of Public Health.

That figure includes medical costs like doctor visits, prescriptions and occupational and speech therapy, as well as expenses for things like special education, camps and child care, said Michael Ganz, the author of the study, who is now a health care consultant.

"It can cost \$3.2 million to take care of an autistic person over the course of his or her lifetime," the study said.

More families are grappling with the disorder than ever before. One of every 110 8-year-old children in the United States has been diagnosed with autism — and one of every 70 boys, according to the latest survey from the Centers for Disease Control and Prevention, released last fall. That is up from one in 150 children in a comparable report released in 2007.

"The numbers are just amazing," said Pat Kemp, executive vice president of the advocacy group Autism Speaks, "Unless we attack this like a national health crisis, we're going to have a huge economic crisis on our hands."

Certainly families feel the financial strain. Many health insurance policies do not cover autism treatments, while those that do often have severe limits. And there is very little government or private financial assistance available.

In many cases these children will need assistance all their lives, Mr. Ganz points out. Making sure there is money for the future is something else parents worry about.

When his sons received their diagnosis, Mr. Sell was practicing personal-injury law in Texas, and he began paying for many of their treatments from his own income and savings. In 2005, as he became more involved in autism issues, he joined the staff of the Autism Society of America in Bethesda, Md., where he is now a vice president.

His sons are now 15. One, Joe, is talkative and considered “high functioning.” The other, Ben, is nonverbal with profound autism.

“What works for one child doesn’t necessarily work for the other,” Mr. Sell said. “So we’re talking about finding and paying for twice as many treatments.”

In the early years, the Sell family had some autism coverage under Mr. Sell’s health insurance. But claims for certain therapies, tests and treatments were often denied. “I was very aggressive about appealing those denials, and I often won,” Mr. Sell said.

But even with coverage, Mr. Sell found he needed to pay enormous amounts out of pocket to come close to giving his sons the 20 to 40 hours of behavioral therapies each week that were often recommended. (Eventually, as discussed below, Mr. Sell was also able to obtain financial assistance through a special part of the Medicaid program.)

Although direct financial support may be scarce and hard to obtain, there are several autism information and advocacy groups that routinely help parents navigate financial hurdles. Here is a road map parents can use to get started.

CHECK YOUR INSURANCE Coverage for autism treatments is still far from common, but it is improving. Some large employers offer policies that cover treatment, and 15 states have passed laws mandating at least some autism-related coverage. The Autism Society’s Web site lists the relevant states. (That section of the site is still under construction, but you can scroll down to see the states.)

In addition, Maine and New Hampshire both have legislation pending that could pass soon, Mr. Kemp said.

If you do have coverage, watch for limitations. Because treatment for autism is so individualized, there are few uniform standards or protocols for insurance companies to follow. That means parents often have to argue that a certain therapy or treatment is necessary. Also, be sure to check any caps on treatment, Mr. Sell warns. What may look generous — say \$36,000 a year — can be spent quickly. Or there may be limits on how many sessions of a particular type of therapy will be paid for each year.

And you will want to coordinate your insurance coverage with the services you may be receiving from your child’s school. If an occupational therapist sees your child regularly in school, for example, you may want to save your insurance dollars for social interaction therapies.

In addition, you may need to be especially aggressive about coverage for some medical conditions. Gastrointestinal problems, for instance, are extremely common in autistic children.

Mr. Sell found himself fighting for such coverage for Ben, his nonverbal son. The insurance company had denied the claim for gastrointestinal testing, saying that because Ben’s behavior problems were related to autism, the testing was not covered.

Mr. Sell, convinced Ben was in pain and could not tell anyone what was wrong, appealed and won. The tests showed that Ben had ulcers and lower-intestine problems that still occasionally flare up and require treatment.

MEDICAID WAIVERS Some states offer Medicaid coverage for children with autism without taking the family’s income into account — only the child’s diagnosis. This is usually reserved for fairly serious cases but is worth

exploring, Mr. Sell said.

"This was a godsend for us," he said. The waiver, he said, allows families access to services that private insurance won't cover and that they wouldn't be able to afford otherwise.

With the waiver, Mr. Sell was able to get more home-based speech and occupational therapies for his sons to supplement the sessions they receive at the public school they both attend. Medicaid also covers recreational therapy during which a specialist takes Ben and Joe on hikes and other outings, giving the parents some downtime.

To see if your child is eligible for a Medicaid waiver, go to the Centers for Medicare and Medicaid Services Web site and [click on your state](#).

Because Medicaid is one of the few government lifelines available, waiting lists for waivers can be extremely long. Mr. Sell, for example, waited nine years to get waivers for his sons.

"Just go ahead and get on the list and try not to be too discouraged," advised Mr. Sell. "Many states are moving faster now."

GO LOCAL Many autism advocacy organizations, including Autism Speaks and the Autism Society of America, are affiliated with local chapters throughout the country. In addition, most states, counties, towns and cities provide lists of local autism resources and support groups.

It is people in the local groups who will know all the resources available. They can also help you keep up with the latest research, so you don't spend time and money chasing the many unsubstantiated "cures" out there. They will also have lots of practical advice, like which dentists, optometrists and even barbers are good with autistic children.

"You think going to the barber is no big deal?" Mr. Sell asked. "Just try it with an autistic child."

OTHER RESOURCES A handful of organizations like [Easter Seals](#) and the [National Autism Association](#) offer financial help to struggling families. [Autism Family Resources](#) and [United Healthcare Children's Foundation](#) also offer grants to pay for autism treatments.

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